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## **Final Report**

**Aging Families and Breast Cancer**

**DAMD17-00-1-0215**

**Department of the Army**

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**June 11, 2004**

Dr. Raveis would like to acknowledge the special contribution and dedication of the rest of the study team.

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## I. Introduction

Adult daughters, in their support provision role, will have intimate knowledge of their mother's cancer experience. The emotional stress of having to provide assistance and support to their ill mother, is likely to be compounded by their close identification with their mother's health situation. This exploratory research investigation has four technical objectives: (1) To explore how daughters' caregiving experiences contribute to their perception of cancer risk; (2) To examine how daughters' perception of their cancer risk affects their careprovision (i.e., quality of their relationship with their mother, their commitment to caregiving, their provision of emotional support and illness-related assistance); (3) To investigate how daughters' perception of their cancer risk affects the distress and burden they experience as a caregiver; and, (4) To assemble information that will inform development of a risk profile that could be employed to target daughters at need for educational intervention and professional assistance to enable them to retain their caregiving role, perform their support responsibilities adequately and meet their mothers' needs for support and assistance.

To accomplish the study objectives, we used a methodology well suited to the exploratory nature of the investigation-- qualitative data gathering (in-depth interviews) and data analytic techniques (e.g., thematic and content analysis), to obtain detailed information about the cancer experience and provision of support by adult daughter caregivers of breast cancer patients. The study sample consisted of older women diagnosed with breast cancer and their adult caregiving daughter. Study data was collected from 61 adult daughter-patient dyads. Caregiving daughters participated in an in-depth and brief survey. Patients completed a telephone survey.

Content analyses of the caregiver daughters' narratives informed our understanding of the psychosocial concerns impacting caregiving daughters following their mother's breast cancer treatment. As described below, their accounts affirmed that being a source of support and assistance to their ill mother provided them with intimate knowledge of the patient's cancer experience that impacted their understanding of the disease and their perception of cancer risk. Simultaneous with their efforts to be supportive of their ill mothers, daughters were faced with processing the news that they themselves were now at increased risk for breast cancer. The daughters' accounts documented the emotional crisis that this information engendered, as it challenged their previously held beliefs about immunity from cancer. With their new status as a woman with a family history of breast cancer, they confronted personal life and death concerns that mirrored those they held for their mothers. Daughters who were already living with a family history of breast cancer, regarded their mother's diagnosis as further confirmation of their family's vulnerability to breast cancer. By affirming a long-feared reality, this development enhanced long-held fears of personal vulnerability. For some, it also served to increase their sense of disease inevitability and confirmed their previously-held belief that this was what the future held for them..

## II. Body

### Study Purpose and Rationale

Limited attention has been given to the breast cancer experience in older women. Even less is known about the psychosocial issues experienced by the families of older breast cancer patients [Biegel et al., 1991; Massie et al., 1989]. With the continuing shift of cancer care to community-based care, there is a growing need to understand the costs to the family of the cancer experience [National Cancer Institute, 1999]. In particular, adult daughters, who are likely to be a primary source of support and assistance to older women, have not been a major focus of research investigations or supportive services although they are likely to be experiencing a high demand for emotional support themselves. Adult daughters, in their support provision role, will have intimate knowledge of their mother's cancer experience. The emotional stress of having to provide assistance and support to their ill mother, is likely to be compounded by their close identification with their mother's health situation. Daughters of breast cancer patients are a potentially vulnerable population. They are likely to lack the support they may need to deal with their own cancer risk fears.

Investigations have documented a heightened fear of breast cancer risk among first degree female relatives once a relative has been diagnosed with breast cancer. [Lerman et al., 1993; Kash et al., 1992], especially among younger women at high risk [Lerman et al., 1994; Schwartz et al., 1995]. A substantial proportion of women at-risk for familial breast cancer hold exaggerated perceptions of their risk [Lerman et al., 1995] and for some the perceived threat of breast cancer is associated with a paralyzing sense of cancer-related worry that severely impacts their ability to function on a daily basis [Lerman et al., 1993].

Several studies have indicated that daughters of breast cancer patients develop exaggerated concerns that they will also develop breast cancer [Kelly, 1983; Wellisch et al., 1991; Wellisch et al., 1992]. Such fears can adversely impact on the mother-daughter relationship, contributing to conflicted, strained interactions [Peters-Golden, 1982; Wortman, 1984], impeding daughters' support provision. Daughters' awareness of their heightened risk for breast cancer could increase the strains associated with careprovision and impede their ability to meet their mother's practical and emotional support needs. It may also impact their ability to provide practical assistance. Studies have also documented that daughters' relationships with their mothers were more likely to deteriorate when mothers had a poorer prognosis, poorer emotional adjustment to their cancer or more deforming surgery [Lichtman et al., 1985].

Prior work we have conducted has indicated that unmet patient needs for emotional support and practical assistance [Raveis and Karus, 1999] and unsupportive network interchanges [Siegel et al., 1994; Siegel et al., 1997] can detrimentally impact patients' psychological well-being. It may also impact physical recovery and survival. The necessity, then, for research that will inform the psychosocial needs of families is evident. On a national

leadership level the National Coalition for Cancer Survivorship has mandated that the patient and family should be seen as a unit of care [Claus et al., 1996]. They argue for the importance of exploratory studies that address the issues associated with the impact and consequences of cancer care on family caregivers and rate this topic as one of the most important areas for psychosocial oncology research over the next decade. Similarly, the National Cancer Institute (NCI), has acknowledged the necessity to focus attention on understanding the needs of families affected by cancer and the importance of developing appropriate interventions based on these needs [Cole et al., 1996]. NCI broadly defines cancer survivors as anyone (e.g., family members) impacted by the cancer experience.

### **Research Aim and Technical Objectives**

This investigation was initiated in response to these national leadership concerns. The study's overall research aim is to obtain exploratory, descriptive information that will inform this critical gap in psychosocial oncology and provide insights for policy and program development. Information obtained through this investigation will increase understanding of what are the psychosocial needs and concerns of adult daughters affected by breast cancer. Specifically, the research design permits an exploration of the issues daughters involved in their mothers' careprovision encounter during treatment initiation into the survivorship period. An in-depth understanding of these issues is needed to begin to delineate the types of educational efforts and supportive services that need to be developed for this at-risk, vulnerable population.

This exploratory research aim translates into four technical objectives: (1) To explore how daughters' caregiving experiences contribute to their perception of cancer risk; (2) To examine how daughters' perception of their cancer risk affects their careprovision (i.e., quality of their relationship with their mother, their commitment to caregiving, their provision of emotional support and illness-related assistance); (3) To investigate how daughters' perception of their cancer risk affects the distress and burden they experience as a caregiver; and, (4) To assemble information that will inform development of a risk profile that could be employed to target daughters at need for educational intervention and professional assistance to enable them to retain their caregiving role, perform their support responsibilities adequately and meet their mothers' needs for support and assistance.

### **Study Design and Field Procedures**

**Study Design.** Very little empirical research has been focused on understanding the experiences of older breast cancer patients. Even less attention has been focused on the adaptational challenges facing their familial caregivers. To accomplish the study objectives, we used a methodology well suited to the exploratory nature of the investigation-- qualitative data gathering (in-depth interviews) and data analytic techniques (e.g., thematic and content analysis), to obtain detailed information about the cancer experience and provision of support by adult

daughter caregivers of breast cancer patients. Given the dearth of research in this area an exploratory research investigation was a necessary first step.

Qualitative research is often used as an exploratory research strategy when little is known or understood about the phenomenon under investigation. A principal advantage of qualitative research is the ability to achieve dense description on the diverse range of factors that influence the phenomena under investigation. Such an approach is key to generating insights or hypotheses about phenomena that are not well understood or for which key variables may not be adequately identified. It enables the researcher to discover the respondent's "definition of the situation" and to understand their experiences as they are lived by taking into account the meanings they ascribe to events and circumstances in their lives, and the cultural, social and contextual circumstances that may shape these processes [Strauss, 1987; Blumer, 1969]. Meaning and comprehension is generated inductively in the analytic process and is intimately linked to the data.

**Sample.** The study sample consisted of older women diagnosed with breast cancer and their adult caregiving daughter. The patient sample was accrued from the pool of eligible breast cancer patients in treatment at the Herbert Irving Comprehensive Cancer Center at New York Presbyterian Columbia University Medical Center. The center catchment area includes diverse socioeconomic and racial/ethnic neighborhoods. The patients were asked to nominate a daughter (if any) who was involved in their care (i.e., provided them with informal support and assistance). For the caregiver-patient dyad to be eligible the patients had to be in active outpatient treatment, older adults (age 45 and older), have localized cancer (at least a third of the patient sample) or regional/distant disease (at least a third of the sample). Their adult caregiving daughter had to be 18 or older, a biological daughter, not have a personal history of cancer and have provided practical assistance and/or emotional support to their mother since her breast cancer diagnosis. These sampling criteria ensured diversity in the sample and illness experience.

**Screening and accrual** Potentially eligible patients were identified through an ongoing review of the hospital's admission and discharge records. All potentially eligible patients were sent a letter notifying them of the study. The letter also contained all the elements of informed consent and included a return post card with a check-off box so that persons who did not wish to be contacted could mail it back indicating that they were not to be contacted about the study. Following the mailing a clinician researcher telephoned potential participants to discuss the study further, determine their eligibility and, if they were interested in participating, determine whether the patient had an adult daughter who was involved in careprovision. Patients were assured that their participation was entirely voluntary and would have no effect on their medical treatment at the hospital center. The clinician researcher then obtained permission and contact information from the patient to contact their daughter for study participation. The caregiver daughter was sent a letter, followed by a telephone conversation with the clinician researcher about the study. During this telephone conversation an appointment was made for the face-to-face research meeting. At the research meeting the caregiver daughter signed the informed consent form.

Only those patient-caregiver daughter dyads in which both members were willing to participate were accrued. In a few instances, the patient was interested in the study but was too ill to participate. When this occurred permission was obtained for the caregiving daughter to complete a proxy patient survey. The proxy survey was an abbreviated version of the patient survey, consisting of those sections where the daughter would be a knowledgeable reporter. Five proxy surveys were conducted. Accruing seriously-ill patients into the sample by permitting a proxy report ensured that a broader representation of illness conditions were included in the study sample.

A total of 484 potentially eligible patients were identified through medical record review and sent letters. Of these 246 patients were willing to be screened for study eligibility, 106 patients returned a postcard requesting no further contact, 79 were reached by telephone and refused to be screened, three patients were deceased and 50 were unable to be reached despite repeated telephone attempts. Of these 246 patients who agreed to be screened, 74 patients were determined to be eligible and interested in participating, 102 were ineligible because they did not have a daughter, 59 were ineligible because their daughter did not provide any caregiving and eleven were ineligible for other reasons. We obtained study data from 61 of these 74 patient-caregiver daughter dyads, a completion rate of 90.5%. No study data was obtained from nine dyads because the daughters decided to withdraw from the study prior to data collection. For two other dyads, the daughters declined study participation after their mother agreed to participate. One patient decided to withdraw prior to the survey collection and one daughter was unable to be contacted for accrual despite repeated attempts.

**Sampling strategy.** Qualitative studies are not designed to provide prevalence estimates or trend analyses. Rather, they are used for exploratory, descriptive investigations whose objectives are hypothesis generating, not hypothesis testing. Qualitative research is not designed to statistically document the frequency of an event or occurrence in a population, but rather to obtain a comprehensive range of responses or issues on the phenomena of interest (e.g., experiences of women at risk for familial breast cancer caring for their mothers diagnosed with breast cancer). Collecting data from a diverse sample of respondents will ensure that the data contain descriptions of common occurrences, as well as unique or infrequent experiences. A key element in qualitative research is collecting data until "theoretical saturation" or redundancy is achieved – the point at which the experiences of an additional informant does not raise any new issues or add any additional insights [Strauss, 1987]. Methodologists readily acknowledge that it is difficult to anticipate or justify a necessary sample size for saturation to be reached. Indeed, the sample size needed is often only able to be determined in the course of the data collection, through concurrent ongoing data collection and analysis of the responses to substantial issues of interest [Arcury and Quandt, 1998; Miles and Huberman, 1994].

Nonetheless, it was necessary in planning this investigation to estimate what would be a reasonable sample size for this exploratory investigation. Based on our team's prior experiences in conducting qualitative investigations of illness-related concerns and behaviors of diverse

population groups, we conservatively estimated as an upper limit that a sample of 80 patient-caregiver daughters would be adequate to achieve theoretical saturation. As described below, although considerable time and effort was expended to accrue and collect data from every eligible mother-daughter dyad that was identified, we encountered a number of challenges that prevented us from achieving this target sample size (see below). However, analysis of the rich narrative accounts we obtained from the caregiving daughters supports that saturation on our phenomena of interest was attained with the mother-daughter dyads in our sample.

**Challenges in sample recruitment.** The identification and recruitment of the mother-caregiver daughter dyads presented a number of challenges. The process proved to be very labor-intensive and time consuming. Our prior experience in identifying and accruing patient-familial caregiver dyads for other research we had conducted, informed our recruitment strategies for the present investigation (i.e., identification of the patient sample from hospital records, nomination of caregiver by patient). While this was an efficient and effective approach to sample recruitment in our other studies, it proved less effective in identifying and accruing this vulnerable, at-risk population. As delineated below, we encountered several challenges in sample recruitment.

***Mothers as gatekeepers.*** Some mothers were very protective of their daughters and declined study participation once they realized that their daughters would be approached to participate as well. Some of the comments that these mothers shared with the clinician researcher during the screening process clearly indicated a reluctance by these mothers to further burden their caregiver daughters with participation in the study, despite their own interest in and willingness to participate.

***Caregiving daughters are the “sandwich generation”.*** Many of the adult caregiver daughters were at that stage of the lifecycle where they were involved in multiple roles, as wives, mothers, and employees, in addition to their involvement in their mother’s care. The data collection methodology presented barriers to their study participation. For a number of caregiving daughters, then, it was difficult for them to allocate the time necessary for an in-depth interview given the demands of their daily life. In fact, as discussed above, nine daughters who initially agreed to participate in the study, ultimately decided to withdraw because of their other time commitments. In five of these instances the daughters decided to withdraw after having made and postponed their interview session more than once.

In general, we found that even for those daughters who did participate in the study, we needed to devote a considerable amount of time and effort to conduct their in-depth interview. It was not uncommon for daughters to postpone their interview appointments for several weeks or cancel and re-schedule multiple times due to competing demands on their time. We learned early in the field period after two daughters withdrew from the study without completing their interview that we should not administer the mother’s survey until the caregiving daughter had participated in the in-depth interview. This policy ensured that the mother’s survey responses

were temporarily linked to their daughter's report.

***Daughters reluctant to relive this difficult period in their lives.*** Understandably, there was a reluctance on the part of some daughters to participate in an in-depth face-to-face interview that required them to review and reflect on their mother's illness experience and its impact on their lives. While some daughters welcomed the opportunity to give voice to their experience, others preferred to avoid recounting these events.

**Data Collection Procedures.** Data was collected from three sources: adult caregiving daughters, older patients (i.e., mothers), and patients' medical records. Prior to the actual initiation of the data collection, the caregiving daughter survey schedule, topic guide and patient survey schedule were extensively pre-tested. The sequencing and timing of these instruments were established and any necessary revisions were made before field activities were initiated. As part of the pre-testing we assessed potential respondent burden.

Adult caregiver daughters participated in a face-to-face research meeting with a female clinician researcher. Daughters completed a 50 minute questionnaire and a one and one-half hour in-depth interview that was audiotaped with their permission for later transcription and narrative analysis. The meeting was scheduled at their convenience and held at the research offices located three blocks from the medical center or at a location convenient to the daughters, such as their home. At the end of the in-person meeting, caregiver daughters were given a \$30 honorarium to compensate them for their time and effort. They were also reimbursed for their travel expenses in coming to the session (i.e., parking fees, taxi, subway, bus, or train fare) and any childcare costs they may have incurred.

Patients completed a 40 minute survey, administered over the telephone by a female research clinician. Telephone interviews reduced patient burden as they were administered at a time convenient to the patients. Canceled interviews were easily rescheduled. The survey was designed in sections so that it could be administered over more than one session should patients feel too ill or fatigued to continue. We had successfully conducted telephone interviews with older cancer patients that were over an hour in length in prior research [Raveis and Karus, 1999], and we did not encounter any problems collecting information from the patients in this study. The New York area has a high level of telephone coverage, even within the lower socioeconomic neighborhoods [Thornberry and Massey, 1988] so the telephone data collection methodology did not introduce any sampling bias.

**Interviewers background, training and supervision.** Interviewers were masters-level social workers or health care professionals. They were trained in conducting research interviews so that the proper neutrality and professional distance were maintained. Training included instruction in the use of the survey schedules to ensure that complete and relevant data were recorded for each item. Interviewers were also trained and advised to look out for excessive signs of depression and/or anxiety and, as necessary, to offer appropriate referrals to mental

health professionals in the community or at the medical center complex. Prior to conducting any data collection the interviewers conducted pilot data collection sessions as part of their training. Their interviewing technique was reviewed to identify strengths and weaknesses. Additional training was provided as necessary. Bilingual interviewers were available for participants who preferred that the data collection be conducted in Spanish. We had available a team of trained clinicians who had served as interviewers on earlier studies.

A *Procedures Manual* was developed to use for interviewer training. This manual provided interviewers with an overview of the study and detailed for them important issues related to the interviewing procedure. This included a discussion of their roles as interviewers, the importance of maintaining the respondents' confidentiality, how to establish rapport during the interview situation, how to administer the survey schedules, and use of the topic guide in conducting the in-depth interview. Also addressed were potential problems/queries that could arise during the data collection. A separate section in the manual dealt with specific field procedures such as what to do if more than one session was required to complete an interview and how to evaluate when a patient proxy survey was needed. A glossary of medical terminology related to cancer issues was included, which the interviewers could review and use as a reference guide if necessary.

Throughout the data collection period, we continued to monitor the quality of data obtained from the interviewers by listening to a randomly selected subset of in-depth interviews to assess that interviewers maintained neutrality, facilitated spontaneous flow of material through the use of non-directive and unstructured questions, and used appropriate transitions to move the discussion from one topic to another. We also evaluated the adequacy of the range, depth and personal context achieved during the in-depth interviews. Each daughter and patient survey was reviewed and edited upon completion to ensure complete and correct administration of the schedules. Ongoing project supervisory sessions were held to discuss interview techniques and maintain uniformity and continuity in the data collection process.

### **Measures.**

The major substantive components of the caregiving daughters' in-depth interview and survey schedule, the patient survey schedule and the medical record abstraction are described below and copies are included in the appendix. The topic guide for the in-depth interview and the daughter and patient survey schedules were translated into Spanish and used as necessary.

**Caregiving daughter in-depth interview.** The in-depth interview was the primary data-gathering technique with the caregiving daughter. In-depth interviews use nondirective and unstructured questions to elicit the daughter's own construction or interpretation of their situation [Merton et al., 1956]. This involves specific procedures and techniques to ensure the quality and validity of the data. These include explicit criteria for evaluating the adequacy of the data as it is being collected [Merton et al., 1956]: 'range' (extent the full scope of data about the external

situation and the person's response to it is elicited); 'specificity' (extent data on specific aspects or dimensions of the situation to which the respondent reacted is obtained); 'depth' (extent interview provides information on the affective, cognitive and evaluative meanings of the situation for the respondent); and 'personal context' (extent interview elicits the respondent's characteristics and prior experiences which shape the respondent's personal and idiosyncratic meanings).

Throughout the interview, the clinician interviewer encouraged the daughter to talk freely, spontaneously and in-depth about a variety of topics. The interviewer facilitated the flow of information about the issue under investigation primarily through neutral probes, unstructured questions and by focusing on general topics or issues, probing only to encourage elaboration or clarification. This process enabled the daughter's story to emerge spontaneously, in context, with minimum input or influence from the interviewer. The advantage of this data collection methodology is that it has the unique ability to elicit the participant's own frame of reference for the phenomena under investigation. Whereas structured interviews rest on the assumption that there is a shared meaning among participants of the terms used to describe their situations and experiences, unstructured in-depth interviews require no such assumption, thereby allowing the clinician interviewer to examine whether or not participants employ such terms in the same way [Merton et al., 1956].

An important element of the in-depth interview is the use of a topic guide. The guide is not a structured interview schedule. Rather, it is an outline of topics or issues that conceptually focuses the interviewer and reflects our evolving understanding of potentially important elements of the situation, based on prior research and clinical experiences. The respondent is permitted to talk spontaneously, determining the flow of the interview and introducing any topic considered relevant to the experience under investigation. However the topic guide helps ensure that important areas, developed in advance, are covered. The interviewer tries to ensure that the respondent remains focused on the problem of interest and that all topics in the guide are covered, facilitating transitions from one topic to another when the respondent makes a direct or indirect reference to some element in the guide. As the data gathering and analysis of the data proceeded, we continued to refine elements in the guide to reflect new elements that emerged from our analyses.

Topics the caregiver daughter was queried about included: circumstances leading to her assumption of caregiving, her reactions to her mother's illness and treatment, her level of caregiving involvement, changes in her relationship with her mother since the illness/involvement in caregiving, her assessment of her mother's support needs and her evaluation of her caregiving and support provision. The caregiver daughter was also asked to talk about her perceived vulnerability to cancer and the personal risk factors she believed she had. Availability and adequacy of her own support, as it related to her caregiving and personal cancer concerns was also explored.

**Caregiver Daughter Survey.** Standard sociodemographics and lifestyle data was obtained from the daughters. They were also asked to report on the *quality of the caregiver daughter - mother relationship* and its change since the patient's cancer diagnosis, using an abbreviated version of the Network of Relationships Inventory [Furman, 1996]. They completed a four-item *perceived predictability of illness measure* (4 items from the Mishel Uncertainty in Illness Scale [Mishel, 1981]), a six-item measure of *perceived personal control over the illness* [Affleck et al., 1987], the Center for Epidemiological Studies of Depression scale (CES-D), a widely used, validated and reliable 20-item measure of *depressive symptomatology* [Radloff, 1977; Radloff and Teri, 1986] and the 20-item State Anxiety Scale (STAI-S), a widely used, validated and reliable measure of *anxiety* [Spielberger, 1983]. Daughters also reported on caregiving consequences in five *burden* domains -- physical, time, employment, financial, and social [Raveis et al., 1998]. They completed measures of *caregiving responsibilities* [Raveis et al., 1999] and *filial obligation (i.e., caregiving commitment)* [Cicirelli, 1993]. Daughters reported on the *impact of their mother's breast cancer* using the Impact of Event Scale (IES) [Horowitz et al., 1979]. This 15-item measure has an Intrusion and an Avoidance subscale. The former measures the intrusiveness of thoughts and feelings about a mother's breast cancer and the latter measures the frequency of efforts to avoid thoughts or feelings about the event. The measure has been previously used to assess the stress impact on women who are at increased risk for breast cancer [Audrain et al., 1997; Croyle et al., 1997; Lerman et al., 1995; Lerman et al., 1996; Schwartz et al., 1995]. Daughters provided information on family history of breast cancer, age at menarche, childbearing history, history of breast biopsies and age at biopsies. This information was used to create an assessment of the "*objective probability of developing breast cancer in the next five years*", derived from the formula defined by Gail et al. [Gail et al., 1989]. Their *perceived risk of developing breast cancer* was assessed using 4 items taken from previous studies of women at increased risk for the disease [Audrain et al., 1997; Schwartz et al., 1995]. Daughters also reported on their practice of *breast self-examination* and their *use of mammogram and clinical breast exams*.

**Patient survey.** Patients were also asked standard *sociodemographic and lifestyle data*. They reported on the *quality of the caregiver daughter-mother relationship* and its change since their cancer diagnosis, using an abbreviated version of the Network of Relationships Inventory [Furman, 1996]. Patients completed the four-item *perceived predictability of illness measure* (from the Mishel Uncertainty in Illness Scale [Mishel, 1981]), the six-item measure of *perceived personal control over the illness* [Affleck et al., 1987], a measure of *depressive distress*, the Center for Epidemiological Studies of Depression scale (CES-D) [Radloff, 1977; Radloff and Teri, 1986] and a measure of *anxiety*, the 20-item State Anxiety Scale (STAI-S) [Spielberger, 1983]. Patients reported their *need for support/assistance with activities of daily living (ADLs) and other illness-related tasks*, as well as their *formal and informal provider(s) of assistance* [Raveis and Karus, 1999].

**Medical records abstracted.** Information was collected from the patient's hospital medical records on *extent of disease at diagnosis* (i.e., local, regional, or metastatic); *location of metastasis* (if applicable); *type of treatment regimens* (i.e., surgery, chemotherapy, and/or

radiation); and *date of breast cancer diagnosis*.

**Confidentiality of study data.** We established safeguards, in our prior research on cancer patients and AIDS patients, which prevent disclosure of participants' identity, diagnoses or participation in our research. The confidentiality of the patients' and their caregiver daughters' surveys and interviews are protected with utmost care. All field materials (i.e., patient and caregiver daughter surveys, daughter in-depth interview audiotapes and transcript files) have an assigned code number to prevent accidental disclosure of the subjects' identity. The data is kept in locked file cabinets in the PI's research offices. The patient and caregiver daughter's identifying information (address files, signed consent forms), are stored in a different locked file separate from the research data (i.e., surveys and interviews) obtained from the patients and their caregiver daughters. This identifying information is only accessible to the project investigators.

### **Sample Description**

We wanted to obtain data from a diverse sample of caregiving daughters to ensure an adequate exploration of a range of cancer experiences and responses. Diversity was desired not only on sociodemographic characteristics, but in terms of disease and treatment characteristics and the caregiving situation. As shown below, our recruitment efforts in this aspect were successful.

**Caregiving daughter sociodemographic characteristics.** The sample of caregiving daughters (N=59), ranged in age from 19 to 62 ( $M = 38.08$  years,  $SD = 9.90$ ). Seventy-five percent were white non-Hispanic, 20% were Hispanic, and 3% were black non-Hispanic. More than half (56%) were married and living with their spouse at the time of the interview and 58% were parents. The mean number of people in the daughters' household size was 3.12 ( $SD = 1.56$ ), with 17% of the daughters living alone. Specifically, 59% lived with either a partner or a spouse, 52% had children living in the household, and 19% lived with the patient. Most caregiving daughters (69%) had graduated from college. Almost three-fourths (73%) were employed; 56% worked full time and 17% part time. See Table 1.

**Patient sociodemographic characteristics.** As depicted in Table 2, the patient sample (N=61) ranged in age from 47 to 86 years ( $M = 66.23$  years,  $SD = 8.79$ ). About half (54%) were currently married and living with their spouse; 46% were either widowed, divorced or separated. Forty-one percent had graduated from college. More than half of the patients (55%) were not employed, 20% were working full-time, and 25% part-time. The mean household size was 2.13 ( $SD = 1.06$ ), with 27% of the patients living alone. Fifty-six percent of the patients lived with either a partner or a spouse and 18% lived with their caregiving daughter.

**Disease and treatment characteristics.** More than two-thirds of the patients (69%) had localized breast cancer, about one-third (31%) had regional/metastatic. With regard to type of

treatment, 30% only had surgery, 36% had radiation in addition to surgery, 13% had chemotherapy in addition to surgery, and about a fifth (21%) had a combination of surgery, radiation, and chemotherapy. The mean length of time between diagnosis and the study survey was 233.12 days ( $SD = 84.18$ ). More specifically, for 28% of the patients the length of time since their breast cancer diagnosis was less than or equal to six months, for 67% it was between 6 and 12 months, and for 5% it was greater than one year (see Table 3).

**Patient psychological well-being.** As shown in Table 4, the patients' mean level of depressive symptomatology, measured with the CES-D, was 10.67 ( $SD = 9.70$ ). Eighteen percent reported a level of depressive symptomatology at or above the cut-off for a definition of probable caseness of clinical depression. The patients' mean level of state anxiety, measured with the STAI-S, was 34.84 ( $SD = 11.73$ ).

**Study Participants vs. Non-participants.** We examined the extent to which there were significant differences between the participating patient-daughter dyads ( $n=61$ ) with the eligible non-participants ( $n=13$ ) using information available from medical records (i.e., patient sociodemographics and disease characteristics). Our analysis indicated that the groups did not differ with regard to the patient's race or type of treatment (see Table 5). There were significant differences by patient age and marital status. The patients in the non-participating patient-caregiver dyads were more likely to be very elderly (80 or older) and never married. See Table 5.

**Study Participation by Extent of Disease.** There were no significant differences on caregiving daughters' sociodemographic characteristics by the extent of their mother's breast cancer (local vs. regional/metastatic). See Table 6.

### **Data Analysis**

The analyses conducted on the study data are exploratory in nature and intended to generate rather than test hypotheses. The specific objectives of the study were addressed by a qualitative data analysis approach that uses "constant comparison" [Blumer, 1969]. This analytic strategy involved working back and forth between categories, properties and theoretical propositions regarding the interrelationships between categories, and, the modifications in categories, properties and relationships suggested by new data. It is a method of explanation building [Blumer, 1969] in which the findings of an initial case were compared to a provisional category, property or proposition; this category, property or proposition was then revised as necessary. Other details of the case or new cases were compared against the revision and this revision was revised again as needed. We repeated this process until the area of interest was fully explicated and reached theoretical saturation. Such an analytic approach allowed us to contextualize the findings (i.e., analyze the daughters' perceived personal and experiential contexts). By using the categories and descriptions provided by the daughters to more adequately specify or affirm our initial concepts and relationships between situational factors we were be able to identify tentative hypotheses which were applicable to the daughters' "world view"

[Davies and Fleiss, 1962]. Central to this process was the "thematic" coding scheme.

**Thematic coding of the interview data.** We employed content/thematic analysis to assimilate the rich qualitative data that was obtained from the daughters' in-depth interviews. Thematic analysis guided the systematic identification of comprehensive topics of discourse (themes) present in the daughters' narrative accounts as well as the specification of relationships among these themes and, as appropriate, with contextual factors [Polkinghorne, 1989]. These analyses were achieved by executing a series of analytic tasks that are described below.

The first step in the analytic process was concerned with identifying segments of text that related to the phenomena of central interest (i.e., analytic foci). These foci included: (1) caregiving daughters' perceived risk; (2) their objective risk factors; (3) reactions to their mother's diagnosis; (4) reactions to their mother's treatment (5) interpretation of their mother's treatment and illness-related symptoms; (6) coping resources; (5) health monitoring activities; (8) caregiving situation (9) support resources, (10) caregiving demands; (11) attitudes about careprovision; (11) caregiver burden; (12) quality of mother-daughter relationship; (13) lifestyle changes; (14) emotional and psychological reaction to mother's illness. They represented and became the major organizing structure (i.e., "core" codes) in the coding process.

For each core code, we ultimately developed one or more "secondary codes" that represented either more specific or restricted aspects of the phenomenon, to contextualize it, or to suggest underlying personal meanings. The secondary codes varied in specificity or subtlety depending on the judged substantive value of additional refinements. Thus, for example, any material relating to the quality of the caregiver daughter-patient relationship was assigned a core code (e.g., "A"). We subsequently delineated a variety of secondary codes (i.e, A.1, A.2, ....A.x).

The coding schema were a means of organizing and assimilating the large amount of rich "thick" data that the daughters' in-depth interviews yielded. To ensure that the coding scheme for the core codes and secondary codes were both valid (i.e., well grounded in the data and supportable) and reliable (consistent in meaning), they were systematically developed and well-documented. The complete development process and use of a coding scheme involved multiple tasks in an ordered sequence:

- (1) Two investigators each defined the principal analytic foci listed above in broad terms based on a review of the relevant research, clinical literature and prior research experience. These definitions permitted a shared understanding of what segments or blocks of text would be relevant to a particular core code or secondary code.
- (2) Working independently, they each read a random subset of the transcripts of the daughters' interviews in their entirety to obtain an overview of the participant's situation and knowledge of the entire interview content, since material relevant to the codes of a particular

issue could be dispersed throughout the interview.

(3) They then independently re-read each interview a second time and systematically coded blocks of text relevant to each of the analytic foci defined above.

(4) Each investigator separately identified the themes they saw as relevant to each of the analytic foci defined above. Specifically, they each compiled the blocks of text that supported their own rationale for identifying the presence of a particular theme into a central file to later serve as the basis for developing the criteria for the core codes and secondary codes.

(5) After individually identifying themes from the in-depth interviews, the investigators worked together to reconcile and compile a single list of themes.

6. The investigators prepared a coding manual establishing a common terminology to describe the themes identified from their reading of the interviews, and a common set of criteria by which to identify them. Each theme corresponding to the analytic foci was assigned a unique numerical value (i.e., A, B, C, etc.), reflecting the core codes. Similarly, each specific aspect of a particular theme was also given a unique value (i.e., A.1, A.2, A.3, B.1, B.2, etc.), representing the secondary codes. Working in collaboration they developed the clearest possible criteria for assignment of a particular core code or secondary code, based upon a synthesis of the criteria they had each independently used to establish the presence of a particular theme (core code) or a specific aspect of a particular theme (secondary code). They resolved any disagreement about a theme present in a block of narrative material through a discussion of the reasons why each assigned a particular theme, then they compared this material with any other material (if any) classified under the same theme as proposed by either investigator to decide which seems more conceptually congruent with the material under dispute. Appropriate multiple theme codes were assigned to the same material.

7. Using the coding manual, coders, working independently, read each in-depth interview and then assigned a core code or secondary code numeric to each block of text in the interviews.

8. Inter-coder reliability and/or agreement between them was estimated using an appropriate chance-corrected statistic such as kappa for nominal data and the T-index for ordinal data. Since these are already chance-corrected statistics, a coefficient of .60 or higher was considered substantial [Cohen, 1960; Davies and Fleiss, 1962; Shrout and Fleiss, 1979].

9. Upon completion of the independent assignment of codes to the interview transcripts, any discrepancies regarding the coding was resolved by a discussion between the coders and verification, when possible, with comparisons of the text with other interviews having the same code or secondary code. In addition, once the assignment of the codes was completed and any discrepancies in the coding resolved, instances of text assigned the same core code or secondary code were examined to confirm that they were indeed instances of the same phenomenon.

**Computer-assisted qualitative analysis.** Once the thematic coding was completed, numbers representing the core codes and secondary codes were inserted into the computer text files of the transcripts wherever textual material relevant to a core code or secondary code was located permitting searching and excerpting of relevant text by code categories. Pertinent coded material was then retrieved, stored in separate text files, and subjected to content analysis.

**Quantitative analyses.** Although the main data collection strategy was in-depth interviewing, the quantitative data from the daughter and patient surveys is being used in three types of analyses. First, this data is used to describe the sample through standard descriptive statistics. Bivariate relationships among these variables is assessed using bivariate correlations or analysis of variance as appropriate. Second, these measures are imported into the coded qualitative files and being used to contextualize the analyses of the qualitative data (i.e., high-low perceived risk of breast cancer). And, finally, by comparing patients' and caregiver daughters' reports on the same measures (i.e., quality of mother-daughter relationship and change in relationship over time) we are able to identify areas of agreement and discordance in their assessments of the impact of the cancer experience on the dyads' relationship.

### **Findings**

In intensive qualitative research, the emphasis is on deriving valid insights into a phenomenon, not on generalizing the findings to populations or universes (i.e., emphasis is on analytic generalization rather than statistical generalization). Thus, our data analysis focused on understanding the daughters' cancer experiences; i.e., fully articulating their reactions to their mothers' diagnosis, the changes they encountered in their relationships with their mothers, and the impact of their mothers' illness and their caregiving involvement on their sense of personal risk and vulnerability to cancer.

When a family member becomes ill, the illness experience has ramifications for the entire family system [Baider et al., 2000; Northouse, 1984]. The focused interviews we conducted with the adult caregiving daughters of breast cancer patients have contributed to our understanding of the existential plight that family members encounter following the cancer diagnosis of a loved one. These accounts have documented that caregiving daughters are a vulnerable population and have provided insights into the impact and implications of a mother's diagnosis on her daughter's life.

### **Exploration of caregiving experience and perception of cancer risk (Objective 1)**

Whereas limited attention has focused on how the cancer experience affects adult children [Germino and Funk, 1993; Wellisch et al., 1996], there has been even less investigation of the ramifications of a cancer diagnosis on adult children who may themselves be at higher risk for developing cancer, such as daughters of women with breast cancer [Oktay, 2004; Tarkan, 1999; Wellisch and Lindberg, 2004]. A family history of breast cancer is indicative of

heightened susceptibility to the disease [Lindblom, 1995; Madigan et al., 1995; Pharoah et al., 1997]. Because of the hereditary component of breast cancer, a daughter learning of her mother's diagnosis is at the same time learning of her own membership in a high risk group. That is, she must integrate her reactions to her mother's illness while simultaneously processing her reactions to her personal susceptibility.

Indeed, as public awareness of a hereditary component to breast cancer risk has grown, investigations have documented an increased fear of cancer and a greater perception of breast cancer risk among women with a family history of breast cancer [Baider et al., 1999; Gagnon et al., 1996; McCaul et al., 1998]. This is further complicated by daughters' tendencies to overestimate their risk of developing cancer [Daly et al., 1996; Gagnon et al., 1996; Kash et al., 2000; Lerman et al., 1994; Lerman et al., 1995; Lindberg and Wellisch, 2001; Meiser et al., 2001; Sagi et al., 1998].

These issues may be particularly exacerbated when daughters are providing care and support to their mothers during her illness. Experiencing first-hand the details of their mother's ordeal, caregiving daughters may find themselves vicariously "living the breast cancer experience" [Chalmers and Thomson, 1996]. The intimate knowledge of their mother's breast cancer experience arising from their caregiving involvement may impact the daughters' sense of personal risk and increase the concerns they associate with the disease. This possibility is supported by Erblich, Bovbjerg, and Baldimarsdottir's [2000] finding that among women with family histories of breast cancer those who had cared for their mothers with breast cancer reported higher levels of breast cancer-specific distress (i.e., intrusive thoughts and avoidance) than those who had not. A similar process has been posited with other diseases in which a family history is associated with increased risk. Prohaska [personal communication] attributes some of the heightened concern and distress experienced by adult children caring for an elderly parent with Alzheimer's to their "seeing Alzheimer's face" and fearing that this fate awaits them in the future.

Content analyses of the caregiver daughters' narratives informed our understanding of the psychosocial concerns impacting caregiving daughters following their mother's breast cancer treatment. As described below, their accounts affirmed that being a source of support and assistance to their ill mother provided them with intimate knowledge of the patient's cancer experience that impacted their understanding of the disease and their perception of cancer risk. Simultaneous with their efforts to be supportive of their ill mothers, daughters were faced with processing the news that they themselves were now at increased risk for breast cancer. The daughters' accounts documented the emotional crisis that this information engendered, as it challenged their previously held beliefs about immunity from cancer. With their new status as a woman with a family history of breast cancer, they confronted personal life and death concerns that mirrored those they held for their mothers. Daughters who were already living with a family history of breast cancer, regarded their mother's diagnosis as further confirmation of their family's vulnerability to breast cancer. By affirming a long-feared reality, this development

enhanced long-held fears of personal vulnerability. For some, it also served to increase their sense of disease inevitability and confirmed their previously-held belief that this was what the future held for them.

***Prompting their comprehension of personal cancer risk:*** The caregiving daughters in the sample talked about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability. These daughters recalled that prior to their mother's diagnosis they had not given much thought to the threat of breast cancer. That changed as this event destroyed any beliefs they may have previously held about immunity from cancer. As one daughter observed, "[I]f it happened to her, it can happen to me." Their new status as a woman with a family history of breast cancer also contributed to some daughters' sense of vulnerability. Commenting on this process, one daughter related: "[Y]ou know, beforehand I felt I had no risk whatsoever. And now, with this, I feel I am much — I am at a higher risk, given my history." As another daughter noted:

I think one of the most dominating issues that I had to deal with this time, because of my age, at this point — I'm older, and what's more of a reality for me is: *This can happen to me.*

The cancer experience was a sentinel event for these women. The following quote presents a clear image of the perceptual shift one daughter experienced following her mother's diagnosis:

I used to have my annual check up, but never thought that in my family this will happens. There has never been anybody in my family with that illness, nobody. . . . This has been an experience that has opened my eyes. It makes you think, "my mother have that illness, I could have it too."

***Careprovision raised awareness of personal risk.*** For some caregiving daughters, it was not the knowledge of their mothers' breast cancer diagnosis that raised their awareness of breast cancer risk, but what their careprovision exposed them to. As one daughter recounted, her involvement in her mother's care, e.g., accompanying her mother to the hospital for her surgery, was the precipitating factor that exposed her to a situation that served as a wake-up call regarding her own risk status:

When I went to the hospital with her, the day that she was having surgery, I saw many young women, which surprised me. I always thought that they were older women, but I saw many women in their thirties — I saw about three or four — who seemed very young to me and it must — it was like a wakening call, just — you know, I realized that anyone's at risk, and no matter how young you are, it — just anyone is at risk and it made me realize that I am even at a *higher* risk, a greater risk than most.

***Providing a call to action to reduce their personal risk.*** This heightened sense of

vulnerability is translated for some of these caregiving daughters into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in preventive health behavior. Daughters related how their exposure to their mother's cancer experience prompted them to a course of action that they believed would enhance their health outcomes in the future:

I think I've — in general have been a little bit more cautious. I don't want to follow her path in not going to the doctor's — that I've done — things I hadn't done recently, like plan to get a physical. Get a mammogram.

Similarly, another daughter echoed the beliefs held by a number of daughters of the values of screening and early detection:

People survive breast cancer; I know that. . . . And the care I give myself, which is a twice a year checkup on my doctor, and once a year mammography and sonography, will be early detection, hopefully, if I do ever have it, get it, *contract* it. Whatever. It will be early stage and it will be "cured," taken care of — I don't even know the right words — survivable.

For some these plans included attempts to engage in a healthy lifestyle. As one daughter explained: "Now I know that I need to be more careful. I have to, you know, be more alert about things because...especially with what I eat and my nutrition which is very important."

***Familial risk prompts family-based action plan.*** Caregiving daughters also described how their mothers' breast cancer generated concerns for the family, i.e., the interpretation of the significance of their mother's cancer experience was an event that was shared among the "at risk" members of the family:

We sat all together and we decided things that we're going to do . . . things that *we* have to do, as ladies in the house and, you know, in the family, we say: We need to go and have a mammogram for each one of us. You know, try to be more alert.

***Recognize the value of screening and health monitoring.*** Even those women who previously were aware of the importance of regular check-ups and mammography now see their value brought home. The following statement succinctly summarized the change in daughters' sentiments regarding screening and monitoring their health status as a consequence of their mother's breast cancer experience: "I feel like sort of this urgent need that I need to start mammograms and start a baseline and keep an eye on it." Similarly, another daughter described how this experience compelled her to be more proactive about her own health: "I *never* did self-examinations. And I — not quite once a month, but I've actually started to do them, which is great and — I want to go get a mammogram."

***Living with risk impacts life quality and alters perceived future .*** While some women

reported how their exposure to their mother's breast cancer experience translated into their being more proactive about their health, for others this awareness of increased risk was also associated with intrusive thoughts, worry and anxiety. As one daughter recounted: "Before I used to go out and enjoyed myself a lot. Now when I go out I feel myself preoccupied all the time, worry." Similarly, another daughter observed that: "It's like always there, in the back of my mind -- thinking about this illness."

Daughters readily acknowledged that their mother's illness altered their own lives, impacting their life quality. They were concerned with how they would be able to cope with this experience, knowing their family history. As one daughter explained: "What would my life *be* like, knowing that I will have this risk factor, and how would that affect me, and *would* it affect my ability to enjoy my health in my day-to-day life."

Similarly, another observed how their mother's illness dually challenged her as she needed to face her concerns about getting breast cancer and also cope with the fears that she would experience at every screening or monitoring exam:

Not only I was *afraid* about the anxiety, as much as the prospect of breast cancer — afraid of what the anxiety would be like of getting a mammogram, or every time, or when there were false positives, or — you know? Just living your life knowing that there's this thing, and you're at risk for it, and it really could happen.

For some at risk daughters, these concerns may also be manifested as hypervigilant monitoring and symptom interpretation.. One daughter explained:

Now any pain that I have I run to the doctor. The other day it happened and I went to my private doctor. . . I just had the mammography done a couple of weeks before that. It is really frightened. ...[A]ny little pain make me think about it. Before, I never thought about it.

**Breast cancer as family legacy.** Some daughters who were already living with a family history of breast cancer, regarded their mother's diagnosis as further confirmation of their family's vulnerability to breast cancer and as adding to their risk of the disease. As one daughter explained:

I definitely feel as though I'm now at a much higher risk for breast cancer than I was. I knew that breast cancer was in our family...but with my mother being diagnosed, and having had her grandmother die of breast cancer, just makes it all that much more — a risk for us. Both for my sister and myself, and my children.

Although for these daughters their mothers' breast cancer may have been an anticipated event, this awareness did not necessarily lessen the emotional intensity of the diagnosis. In fact,

its occurrence, by affirming a long-feared reality, served to enhance long-held fears of personal vulnerability. As one daughter described this experience:

Coming from the family that I came from . . . grandparents who had cancer, et cetera, so I feel like I've always been aware of being vulnerable. At the beginning, I was — when I realized: "Oh, I'm higher risk now." You know? And my cousins, the daughters of my aunt, who had the breast cancer, said: "Oh, well, welcome to the high-risk club — ha, ha, ha." And I didn't — it wasn't a club I was very eager to join. I felt really scared.

For some daughters, knowledge of their mother's breast cancer not only served to increase their perception of risk, but it also contributed to their sense of disease inevitability, reaffirming a previously-held belief that this was what the future holds for them. This perception that breast cancer is an integral part of a family's legacy is dramatically illustrated in the following account:

[F]or me, it kicked up a lot of fears of being a *daughter*, and that — okay, I'm next in line. . . . I once heard my mother say that she always felt like she was waiting for a train, because of our family history. Like it was a train she was waiting to get on. You know? It was like inevitable. And I guess I feel that way now: I'm next.

***Generating concerns for their children's future.*** The diagnosis of breast cancer has also impacted how some caregiving daughters' feel about their family's vulnerability to cancer. As with their own sense of heightened vulnerability, daughters' need to deal with their realization that this risk can impact future generations. As one daughter explained: "I think about my daughter too. Before this I never thought about it; not my mother, nor my daughter, never." Daughters' accounts indicate that their concerns for their daughter's health are more intense than their fears for their own risk status:

Just as I've become more concerned for myself, I've become more concerned for her. . . . You know, because — that's one of the main risk factors is, you know, family history."

These women may also need to cope with intrusive thoughts and worries about their daughter's welfare and what the future may hold for her:

I am always thinking about my daughter... I always think, "one day she will go to the doctor and find out that she has it too".

***Caregiving impacted cancer perceptions.*** Daughters' involvement in careprovision not only contributed to their perception of cancer risk, but it also informed their understanding of the disease experience. This exposure served to normalize or de-mystify the experience for some daughters, i.e., "My mother did what she needed to do". Daughters' exposure to their mothers' cancer experience also served in these instances as a source of comfort or reassurance regarding what they may be facing in the future. As the following account, caregiving daughters who

experienced first-hand what their mother did to deal with her breast cancer threat, they felt hopeful about their own future and were less fearful about the consequences of their increased risk status:

I definitely feel like I'm in a high-risk group, given — my maternal grandmother having it and now my — my mother. But I also feel that, you know, like my *mom* — I mean, knock wood — so far, an early detection — she was early detection and her prognosis now is very *good*. And so, you know, while I worry that I am in this high-risk category, I also know if I'm careful with my mammograms, and that — that there's just such better care and treatment than in the days of my grandmother — when she had a radical mastectomy [sic] but yet it had already spread, you know, all over. .. I just know that I'll just do what I can do and talk to my doctors and — just be proactive for my own care.

For some daughters, however, this exposure to their mother's cancer experience was detrimental. As one daughter acknowledged, her careprovision contributed to her dread of cancer:

It's not something I want, it's just something that I think I need to keep in mind and keep my eyes open to. ...And I'm afraid. Because I've seen what my mother's going through and getting diagnosed and having surgery was the easiest part.

The intimate knowledge of their mother's illness that caregiving afforded also informed some daughters' interpretation of the cause of their mother's breast cancer. One daughter, who was struggling with the ambivalence and uncertainty regarding her personal risk, related:

There's risk factors, of course, and I feel like she had it when she was 70, and I pretty much feel that the hormones were responsible for it. I'm not sure of that, and nobody really knows. But genetically, you know, I do worry about it. But then I never — I never did anything, either, that would set me up for it. But that doesn't mean anything either. . . . I worry about it, but you can't worry about everything. You can be hit by a car tomorrow.

***Contribution of genetic assessment in managing perceived risk.*** For some daughters genetic testing was helpful in resolving the ambiguity about their risk, permitting them to stop worrying about a health threat and focus their attention on other issues. One daughter's statement illustrates how the results of her mothers' genetic testing alleviated some of her concerns and anxieties:

She [her mother] went and got the testing and found out that she was *not* a carrier for the gene. . . . And I felt like, once she was not a carrier for the gene, it just — it was another thing that just — I didn't have to deal with and that was okay, and I knew I could put it in a box and push it away now, because it wasn't an issue.

For others, though, genetic testing did not diminish the uncertainty and irresolution they were living with. As the following daughter's account illustrates, even when her mother's genetic tests results were negative, she continued to hold to her conviction that her mother's cancer had a genetic component:

Well, my mother had the — the genetic testing done and we found out that — that was negative. Which doesn't mean all that much, except for that we don't have *that* gene. We know there's got to be some genetic component in our family, but they haven't allocated which that is yet.

Similar sentiments are expressed in this next quote:

I almost want to have the gene, because I think if I *don't* have the gene, three years from now BRCA3 will come up. Just saying no, you don't have a gene right now, doesn't mean, no, you won't have another gene five years from now.

***Challenged in caring for themselves.*** Caregiving can impede women taking care of themselves, causing them to neglect their own health needs, delay or cancel routine health care, screening exams or other preventive health tasks. Over time, these actions, in a high risk population could delay diagnosis and impede timely intervention. As one daughter observed:

I need to go and see that doctor more often. I don't do that. I take care of everybody, but I — most of the time neglect myself.

***Daughters' perceived risk.*** An examination of the survey responses that daughters provided in response to their perceived risk of breast cancer indicated that, consistent with the research literature [Daly et al., 1996; Gagnon et al., 1996; Kash et al., 2000; Lerman et al., 1994; Lerman et al., 1995; Lindberg and Wellisch, 2001; Meiser et al., 2001; Sagi et al., 1998], daughters in this study had elevated levels of risk perception. Only 25% of the daughters perceived their risk as low. Fifty-three percent perceived their risk as moderate and 23% perceived their risk as high (see Table 7).

This perception of increased risk of developing breast cancer was also evident in the daughters' responses to the individual risk perception items. Almost three-fourths of the women (72%) reported that compared to other women their age, they had either a somewhat or much higher risk of getting breast cancer. In addition, 88% reported that their mother's diagnosis of breast cancer had made them feel that they were somewhat or a lot more at risk for developing the disease.

A little more than half of the women (57%) reported that compared to other women with a relative with breast cancer, their chances of developing breast cancer were about the same, although more than one-fourth (26%) felt that their chances of developing the disease were

somewhat or much higher.

The women clearly perceived that it was "family history" that rendered them at higher risk for developing breast cancer, because 81% of the women reported that compared to other women *without* a relative with breast cancer, their chances of developing the disease were somewhat or much higher.

***Comparison of a 5- year Modified Gail Risk Assessment by daughters' perceived risk.***

In the survey daughters were also asked to provide information on family history of breast cancer, age at menarche, childbearing history, history of breast biopsies and age at biopsies. This information was used to create an assessment of the "objective" probability of developing breast cancer in the next five years, based upon the Modified Gail Risk Assessment [Gail et al., 1989]. We then compared daughters' objective risk of developing breast cancer in the next five years between two groups -- daughters who reported the lowest levels of perceived risk relative to other daughters in the sample (i.e., low perceived risk group) and daughters who reported the highest levels of perceived risk relative to other daughters in the sample (i.e., high perceived risk group). Daughters, who perceived themselves to be at a low risk of developing cancer, scored higher on the objective measure of 5-year cancer risk compared to the high perceived risk group, although the differences between the groups was not significant (see Table 9).

***Comparison of low perceived risk group to high perceived risk group on extent of cancer and time since diagnosis.*** Using the two perceived risk groups defined above (i.e., "low perceived risk", daughters who reported the lowest levels of perceived risk and "high perceived risk", those reported the highest levels of perceived risk ), we examined whether seriousness of their mother's disease or length of cancer survivorship impacted daughters' perception of cancer risk. There were no significant differences observed (see Table 8).

***Caregiving daughters breast cancer screening behavior.*** The daughters narrative accounts revealed a resolve to engage in healthy behavior and initiate a proactive approach to monitoring their health. Our analysis of the daughters' survey responses provided evidence of adherence to this plan of action. Forty-eight percent of daughters 40 or older reported conducting monthly breast self-examinations. Ninety-two percent of daughters 40 or older reported having regular mammograms. The mean number of months since their last mammogram was 9.46 ( $SD = 8.87$ ; over half (52%) had a mammogram within the last 6 months (see Table 10).

***Impact of event/Fear of cancer.*** We also assessed the extent to which daughters were experiencing intrusive thoughts and feelings about their mother's breast cancer and the frequency of their efforts to avoid thoughts or feelings about the illness. This assessment used the Impact of Event Scale [Horowitz et al., 1979]. For the total measure, the mean score was 15.52 ( $SD = 10.63$ ), with a range of 0-75. For the Intrusion subscale, the mean score was 8.96 ( $SD = 6.73$ ), with a range of 0-35. For the Avoidance subscale, the mean score was 6.54 ( $SD = 5.91$ ), with a range of 0-40 (see Table 11). These scores were similar to the scores reported by Erblich and

colleagues [2000] for caregivers with a family histories of breast cancer. In that investigation, women who had cared for their mothers with breast cancer reported higher levels of breast cancer-specific distress (i.e., intrusive thoughts and avoidance) compared to non-caregivers with a family history of breast cancer. Specifically, Erblich et al.'s [2000] investigation reported a mean of 9.1 ( $SD = 1.5$ ) on Intrusive Thoughts and a mean of 10.1 ( $SD = 1.8$ ) on Avoidance for those women who had been involved in careprovision, and means of 4.1 ( $SD = 1.1$ ) and 5.7 ( $SD = 1.5$ ), respectively, for those who had not been caregivers.

***Comparison of low perceived risk group to high perceived risk group on the impact of the illness.*** Comparisons of caregiving daughters who perceived themselves at low risk for developing breast cancer to those who perceived themselves at high risk, with regard to the impact of their mother's illness revealed no significant differences between the groups on the Overall Impact of Event Scale, the Intrusiveness subscale, or the Avoidance subscale (see Table 12).

**Exploration of perceived cancer risk and careprovision - Quality of mother-daughter relationship, caregiving commitment, support provision (Objective 2)**

Researchers have found that fear of developing breast cancer can adversely impact on the mother-daughter relationship, contributing to conflicted, strained interactions [Peters-Golden, 1982; Wortman, 1984], impeding daughters' support provision. Studies have also documented that daughters' relationships with their mothers were more likely to deteriorate when mothers had a poorer prognosis, poorer emotional adjustment to their cancer or more deforming surgery [Lichtman et al., 1985].

Content analysis of the caregiving daughters' narrative accounts affirmed that their careprovision precipitated marked changes in their relationship with their mother. As discussed below, the daughters disclosed how the illness altered their perception of their mother with many for the first time regarding her as vulnerable and susceptible to life's adversities. Their reports delineated how the diagnosis and its implications intensified the mother-daughter bond. Although significant progress has been made in reducing rates of cancer mortality, a diagnosis of cancer is still often equated with a death sentence. For some daughters, then, the cancer diagnosis forced them to confront a life cycle transition with which they felt ill-prepared to deal. The possibility of such a premature loss engendered a cacophony of emotions and a shift in their life priorities, as they reevaluated what was important to them. Daughters shared that their efforts to be protective and supportive sometimes complicated their interactions, as they deemed it necessary to shield their mother from extreme personal or family reactions, out of a belief that such exposure could be harmful and further increase their mother's suffering.

***Cancer diagnosis intensifies bond to their mother.*** Accompanying daughters increased perception of vulnerability to was reports of an intensification of the mother-daughter bond,

perhaps reflecting the close identification with their mother's situation others have noted. These feelings are reflected in the following comments caregiving daughters made regarding their relationship with their mother following the diagnosis of breast cancer:

"I think I learned what she meant to me more than ever. . . . Because, at that time, I looked at things -- I'd say: What if I have this house? And then I said to myself, So what -- what is it good for? It means nothing. Nothing at all."

And also:

"It just made me more aware that I need to love every minute I have with her."

Sometimes this intensification in the relationship was coupled with a shift in the daughters' personal priorities, as reflected in the following account:

I noticed that, all of a sudden, my life, and my world — everything that I planned, in — nothing meant — nothing meant anything to me. . . . I learned what she meant to me more than ever. . . . I'd say: "What if I have this house?" And then I said to myself, "So what — what is it good for?" It means nothing. Nothing at all.

***Caregiving forged a closer bond.*** The intimacy that characterizes careprovision contributed the increased closeness that daughters' reported experiencing with their mothers during the illness course. As one daughter expressed this consequence:

Although we had a good relationship before, I think that it just gave us that extra connection, because now she really felt she could rely on me.

Another daughter explained further:

Even though we had a good relationship, there was a closeness because I always had to be on top of what was going on, and I was always in communication with her, with the doctors. So it was something that brought us closer.

One daughter's acknowledged that the opportunity caregiving would provide her to spend more time together impacted her decision. She explained that her fear of possibly losing her mother was a motivating factor in becoming her mother's caregiver:

"I felt like — maybe this is why I became the caregiver. . . . I was afraid *not* to spend time with her. I was afraid to not be with her. I was afraid to not be around her a lot."

For some, though, their mother's cancer diagnosis posed a dilemma in their relationship that was not easily resolved. As one daughter explained her predicament:

I think before, I had this idea that my mother wasn't going anywhere, that she's always going to be there with me, and I could treat her however I wanted to, and she'll always be there. But then when she got ill, it made me realize that she might not be there forever. . . and then I think maybe I should treat her better. But then, at the same time, I think maybe I don't want to spend that much time with her, because if something happens, then I won't miss her at much.

***Seeing their mothers as vulnerable.*** One change that daughters commonly reported related to their fundamental perception of their mother as strong and invincible. The daughters' involvement in illness-related caregiving contributes to their altered perceptions of their mother. As one daughter reflected:

"She is such an independent and strong and capable person, it's been difficult for me to see her in such, what to me looks like a vulnerable position."

For many daughters, the cancer diagnosis challenged these long-held images of their mother and represented the first time they perceived her as vulnerable or fragile. As one participant confessed:

We call her the Iron Maiden, because she's been through so much, and she just takes it all in stride. And it was the first time that I had actually witnessed her more as, you know, someone who's fragile or delicate.

This strongly-held preconception of their mother as immune to life's trauma also contributed to the difficulty daughters experienced dealing with the news of their mother's cancer diagnosis. Acceptance of this aberrant event compelled daughters to adjust to a changed reality:

For her to get cancer was — I think that's why I went numb, because it just didn't make sense in the way I saw my mother. She — she doesn't *get* sick. . . . I guess it just brought home that she's susceptible to — to disease, and illness.

One daughter's comments succinctly epitomize the life cycle developmental issues that this realization precipitates when she characterized this event as "a pillar of your life coming down." For some daughters, their caregiving involuntarily exposed them to their mother's vulnerability and forced them to experience images they viewed with reluctance. The following daughter's statement illustrates how a simple caregiving task -- accompanying her mother to obtain a wig -- evoked strong emotions and presented profound perceptual challenges:

And I took her; my mother sat on the chair, like getting fit for the wig, crying. And like, again, for me, I did not want to be sitting there watching her, because I don't want — I don't want to see her break down. Like I need my vision of her as her being this strong,

ultimate — my Mom — like my strength, my support. Like the family backbone.

***Seeing their mothers as mortal.*** Closely allied to the awareness that their mothers were not immune from illness and suffering, the cancer diagnosis also precipitated life and death concerns. As one daughter commented, “Once your parents get sick, it changes — things change. . . . Your perception of their immortality — or mortality.” Although mortality in old age may be a normative event, the cancer diagnosis raised the possibility that this loss may occur prematurely. For some daughters, this prospect forced them to confront a life cycle transition with which they felt ill-prepared to deal. This response is typified in the following thoughts one daughter shared:

Even though I know we all have to die, at some point — because I've always lived with her and I have grown so accustomed to living with my mother, that I — it's just like —it's just *impossible* for me to really think that my mother's not going to be there. And, and I think that I have to get maybe a little bit — stronger.

Another daughter expressed holding similar concerns: “Is she going to live through this? How many years is she going to be around? What would I do without her, not having her around?”

The prospect of losing their mother to cancer was especially difficult for daughters who had already experienced their father's death. For these women, their mother's cancer diagnosis raised fears of being orphaned. As one daughter recalled: “One of my initial reactions was, ‘Oh my God, if something happens to my mother, I — I don't have parents anymore.’ So that was a little scary.”

Informed by their careprovision, daughters expressed apprehension over the pain and suffering they envisioned their mother would endure dying from cancer. This contributed to their worries about the possibly fatal nature of their mother's illness. As one daughter described her thoughts: “For me cancer is a bad kind of death sentence that's slow, and painful.” This concern was echoed by yet another daughter, who noted:

So, my biggest fear, definitely, is that she was going to die, followed by that she's going to be in a lot of pain. . . . I don't want to lose my Mom to cancer.” As the following quote illustrates, even those daughters who had readily acknowledged their mother's mortality were troubled by the circumstances they ascribed to the process of dying from cancer: “I *know* I'm going to lose her someday. But *normally*, I'm going to lose her, but I didn't have to lose her *this* way. You know, with being sick. You know, being — you know — with cancer.”

***Cancer diagnosis presents challenges interacting with their mother.*** Daughters report experiencing a variety of challenges interacting with their mother following the diagnosis. One area of concern to daughters is their belief that they need to be a source of support and strength to their mother and to refrain from openly sharing with their mother any worries or fears they may

have about the illness. Such self-imposed constraints may adversely impact the quality of their interaction and could also increase the stressfulness of their caregiving:

“It took me a while for me to really come to terms with reality, that in reality that was cancer. . . and, at the same time, having to present myself to my mother, as if it -- as if nothing was happening. As if, ‘Oh, well, so what? We deal with it, it happens.’ Well, I was *burning* inside. I was suffering. But I could never let my mother know that I was worried, because, number one, I *knew* she was worried.”

And, as illustrated by this next quote, caregiving daughters who are distressed by their mother’s illness may distance themselves from her in an attempt to protect their mother from seeing their distress:

“I went in to see her after the surgery, and it was just horrible. I just couldn’t contain myself. I, I didn’t want to stay with her for very long, because I was just so broken up.”

Daughters perceived that their need to provide care and support to their mothers altered their relationship with her. As one daughter described this occurrence, she explained how needing to protect her mother necessarily altered the information she would share with her mother. She acknowledged how this practice constrained her interactions with her mother and that it impacted the quality of their relationship:

I do talk to her a little bit less about my feelings. Just because I know that she wants to hear them and I know that she wants to know what’s going on, but it’s hard for me to tell her that I’m upset because of things that are going on with her. I know that she knows it. But it is hard for me to express that to her. So that part of our relationship has changed a little bit.

***Changes in the relationship: Comparisons of mother-daughter perspectives.*** An examination of the mother and daughters survey responses provide a comprehensive assessment of the changes in the mother-daughter relationship from the perspective of both the patient and the caregiving daughter. As discussed below, analysis of this data supports the complexities of the mother-daughter relationship in the cancer experience that was delineated in the daughter’s narrative accounts. It adds to the richness of this analysis by providing a dyadic analysis of this

Changes in the relationship between mothers and daughters was assessed with an abbreviated version of the Network of Relationships Inventory [Furman, 1996], comprised of six subscales: Conflict, Satisfaction, Intimacy, Nurturance, Admiration, and Relative Power. Both mothers and daughters completed the inventory, in which they were asked to compare aspects of the relationship *since* the mother’s illness with how it was *prior* to the illness onset (see Table 13).

For daughters, the mean score on the Conflict subscale since the illness was 1.62 ( $SD = .49$ ), compared with 1.85 ( $SD = .66$ ) prior to the illness, indicating that overall there was only a little or some conflict in the relationship and that the level of conflict was significantly reduced since the illness. Indeed, with regard to the extent to which the mothers and daughters get mad or upset at each other, for 69% of the daughters the scores remained the same; for one-fourth of the daughters the scores indicated that the level of conflict got better, and for only 6% the level of conflict was worse since the illness.

Similarly, for mothers, the mean score on the Conflict scale was 1.49 ( $SD = .50$ ), compared with 1.60 ( $SD = .51$ ) prior to the illness, indicating as well that overall there was only a little or some conflict in the relationship and that the level of conflict was significantly reduced since the illness. With regard to the extent to which the mothers and daughters get mad or upset at each other, for 81% of the mothers, the scores remained the same; for 17%, the scores indicated that the level of conflict got better, and for only 2% the level of conflict was got worse. The same pattern was found with regard to responses to other items in the Conflict subscale.

For daughters, the mean score on the Satisfaction subscale since the illness was 3.78 ( $SD = 1.06$ ), compared with 3.58 ( $SD = 1.06$ ) prior to the illness, indicating that they were very or extremely satisfied with the relationship and that the level of satisfaction had significantly improved since the illness. Indeed, with regard to the extent to which the daughters were satisfied with their relationship with their mother, were happy with the way things are, and thought that their relationship with their mother was good, for the majority of the daughters the scores remained the same, while scores for 19%, 12%, and 27% of the daughters, respectively, indicated that the daughters' level of satisfaction was significantly increased.

Similarly, for mothers, the mean score on the Satisfaction subscale since the illness was 4.22 ( $SD = .90$ ), compared with 4.10 ( $SD = .88$ ) prior to the illness, indicating that they were extremely satisfied with the relationship and that the level of satisfaction had significantly improved since the illness. Indeed, with regard to the extent to which the mothers were satisfied with their relationship with their daughter, were happy with the way things are, and thought that their relationship with their daughter was good, for the majority of the mothers the scores remained the same, while scores for 15%, 19%, and 21% of the daughters, respectively, indicated that the mothers' level of satisfaction was significantly increased.

Regarding the Intimacy subscale, there were discrepancies in the reports of mothers and daughters. For daughters, the mean score on the Intimacy subscale since the illness was 2.97 ( $SD = 1.13$ ), compared with 3.10 ( $SD = 1.18$ ) prior to the illness, indicating that whereas they felt very intimate with their mothers, there was a trend toward the level of intimacy becoming reduced since the illness. Indeed, with regard to the extent to which the daughters felt that they tell their mothers everything, they share secrets and private feelings, and they talk about things they don't want other people to know, although for the majority of the daughters the scores remained the same, scores for 17%, 19%, and 17% of the daughters, respectively, indicated that

the level of intimacy was reduced.

For mothers, the opposite was true. The mean score on the Intimacy subscale since the illness was 3.86 (SD = 1.06), compared with 3.45 (SD = 1.13) prior to the illness, indicating that they felt extremely intimate with their daughters and that there was a significant increase in the level of intimacy in the relationship since the illness. With regard to the extent to which the mothers felt that they tell their daughters everything, they share secrets and private feelings, and they talk about things they don't want other people to know, although for the majority of the mothers the scores remained the same, scores for 32%, 24%, and 19% of the mothers, respectively, indicated that the level of intimacy was significantly increased.

This discrepancy between the mothers' and daughters' perspective on their relationship was even more evident with regard to the Nurturance subscale. For daughters, the mean score on the Nurturance subscale since the illness was 3.72 (SD = .86), compared with 2.79 (SD = 1.02) prior to the illness, indicating that they felt that they nurtured their mothers to a very large extent and that their nurturing of their mothers had increased significantly since their mother's illness. With regard to the extent to which daughters felt that they helped their mothers with things they can't do themselves, protected and looked out for their mothers, and took care of them, scores for 83%, 54%, and 77% of the daughters, respectively, indicated that the level of nurturance was significantly increased.

However, for mothers there was a trend in the opposite direction. The mean score on the Nurturance subscale since the illness was 3.10 (SD = 1.04), compared with 3.22 (SD = 1.07) prior to the illness, indicating that whereas mothers felt that they nurtured their daughters to a very large extent, there was a trend toward the level of nurturance becoming reduced since the illness. With regard to the extent to which mothers felt that they helped their daughters with things they can't do themselves, protected and looked out for their daughters, and took care of them, although for the majority of the mothers the scores remained the same, scores for 24%, 4%, and 11% of the mothers, respectively, indicated that the level of nurturance was somewhat reduced since the illness.

For daughters, the mean score on the Admiration subscale since the illness was 3.90 (SD = .96), compared with 3.74 (SD = .98) prior to the illness, indicating that daughters felt that they were extremely admired by their mothers and that they were significantly more admired by their mothers since the illness. Indeed, with regard to the extent to which their mothers treated them like they are admired and respected, treated them like they are good at many things, and liked or approved of the things they do, although scores for the majority of the daughter remained the same, scores for 25%, 19%, and 12% of the daughters, respectively, indicated that the level of admiration was significantly increased.

In contrast, for mothers, the mean score on the Admiration subscale since the illness was 4.00 (SD = .94), compared with 3.95 (SD = .90) prior to the illness, indicating that they felt

extremely admired by their daughters and that there was no significant change in the level of admiration. Indeed, with regard to the extent to which their daughters treated them like they are admired and respected, treated them like they are good at many things, and liked or approved of the things they do, scores for most of the mothers (i.e., 85%, 89%, and 87%, respectively) respectively, indicated that this high level of admiration remained the same.

With regard to the Relative Power subscale, there was again a discrepancy in the perceptions of mothers and daughters. For daughters, the mean score on the Relative Power subscale since the illness was 3.16 ( $SD = 1.04$ ), compared with 2.73 ( $SD = 1.00$ ) prior to the illness, indicating that daughters felt that they had significantly more power in the relationship since the illness than they did prior to the illness. With regard to who tells the other person what to do more often, who tends to be the boss in the relationship, and who tends to take charge and decide what's done, although scores for more than half of the daughters indicated that the balance of power had remained the same, scores for 42%, 31% and 31% of the daughters, respectively, indicated that they felt that they had assumed more power in the relationship.

In contrast, for mothers, the mean score on the Relative Power subscale since the illness was 3.05 ( $SD = .75$ ), compared with 3.30 ( $SD = .74$ ) prior to the illness, indicating that the mothers felt that they had significantly more power in the relationship since the illness than they did prior to the illness. With regard to who tells the other person what to do more often, who tends to be the boss in the relationship, and who tends to take charge and decide what's done, although scores for the majority of the mothers indicated that the balance of power had remained the same, scores for 23%, 15% and 11% of the mothers respectively, indicated that they felt that they had assumed more power in the relationship.

***Correlation of mother-daughter subscale scores.*** Findings of correlation analyses relating daughters and mothers scores on subscales of the NRI suggest that the higher level of conflict reported by daughters prior to their mothers' illness may be associated with poorer outcomes on other aspects of the mother-daughter relationship after the cancer diagnosis. Daughters' perceptions of conflict prior to their mother's diagnosis were significantly and inversely correlated with her current perceptions of satisfaction ( $r=-.247$ ;  $df=56$ ;  $p=.032$ ) and nurturance ( $r=-.322$ ;  $df=56$ ;  $p=.007$ ). There was also a trend toward an inverse relationship with perceived sense of admiration from the mother ( $r=-.212$ ;  $df=56$ ;  $p=.057$ ).

There was also a trend toward an inverse correlation between daughters' perceptions of conflict prior to their mother's diagnosis and mothers' perceptions of nurturance, both before their mother's diagnosis ( $r=-.218$ ;  $df=51$ ;  $p=.060$ ) and currently ( $r=-.183$ ;  $df=51$ ;  $p=.097$ ). Daughters' current perceptions of conflict were significantly and inversely correlated with mothers' current perceptions of nurturance ( $r=-.230$ ;  $df=51$ ;  $p=.051$ ) and admiration from the daughter ( $r=-.274$ ;  $df=51$ ;  $p=.025$ ).

***Comparison of low-risk group to high-risk group on changes in the relationship.*** Low-

risk daughters were compared to high-risk daughters with regard to changes in the relationship with their mother. There were no significant differences between the groups with regard to the overall modified Network of Relationships Inventory scale.

However, with regard to the Conflict subscale, differences were found between the groups. Specifically, scores of the high-risk daughters regarding conflict *prior* to the mother's illness were significantly greater than scores of low-risk daughters, indicating that high-risk daughters experienced a significantly higher level of conflict in their relationship with their mother prior to the illness than did low-risk daughters.

In addition, with regard to level of conflict *since* their mother's illness, there was a trend towards a difference between the groups, such that scores of high-risk daughters were greater than scores of low-risk daughters, indicating that since the illness as well, high-risk daughters experienced greater conflict in the relationship with their mother than low-risk daughters. (See Table 14)

***Caregiving daughter's sense of filial obligation.*** A sense of filial obligation is often the basis of adult children's motivation to care for their aging parents. That is, adult offspring generally endorse the expectation that they should provide help to their parents. Consistent with the daughters narrative accounts, the daughters' survey responses also showed evidence of this motivating factor. Sixty-eight percent somewhat or strongly agreed that married children should live close to parents in order to provide care.

A strikingly high 91% of daughters disagreed with the statement that children should not be expected to do tasks for their parents. Similarly, 88% somewhat or strongly agreed that parents should expect adult children to assist them. Indeed, 86% somewhat or strongly agreed that it is a child's duty to assist parents.

In keeping with this high sense of filial obligation, only 23% of the sample agreed that it is preferable to pay a professional for assistance with caregiving. However, 76% of the daughters somewhat or strongly disagreed with the statement that paying for professional help means that a relative is not taking responsibility and only 19% somewhat or strongly agreed that it is better to give up a job to provide care than to pay a professional.

The total mean for the Filial Obligation Scale was 24.52 ( $SD = 3.61$ ). With a possible range of 7-35, this indicated that the daughters' sense of filial obligation was high. For the subscale, "attitudes regarding filial obligation," the mean was 12.95 ( $SD = 2.44$ ), with a possible range of 3-15, again indicating a high sense of obligation. In contrast, for the subscale "attitudes regarding use of paid help," the mean was 5.78 ( $SD = 1.93$ ), with a possible range of 2-10. This mean was approximately at the midpoint, indicating that they were less committed to doing the actual caregiving on their own; they were open to the idea of using professional help. (See Table 16)

***Comparison of low-risk group to high-risk group on filial obligation.*** Low-risk daughters were compared to high-risk daughters with regard to their sense of filial obligation. There were no significant differences between the groups with regard to the overall scale or the two subscales.

However, with regard to the item concerning whether it is preferable to pay a professional for assistance with caregiving, the high-risk group was significantly more likely to either somewhat agree (46% versus 14%) or strongly disagree (36% versus 7%) than the low-risk group. (See Table X). The daughters' narratives suggested that willingness to include formal help care was often expressed when care was anticipated to require more time and effort than the daughter perceived herself as being able to provide, due at times to logistical issues (i.e., long-distance caregiving, competing family or work responsibilities, etc.).

#### **Exploration of Perceived Cancer Risk and Caregiver Distress and Burden**

**(Objective 3).** The anxiety and concern at risk caregiving daughters may experience over their perceived cancer risk status may be exacerbated by the strain of providing assistance and support to their ill mothers. Content analysis of the caregiving daughters' narrative accounts documented how as a function of their partnership with their mothers in managing their breast cancer, caregiving daughters were confronted on a regular basis with various aspects of the disease and its management. Given that daughters may simultaneously identify with their mother's health condition, their first-hand exposure to the "costs" and ramifications of their mother's breast cancer has added personal significance.

As discussed in greater detail below, daughters' caregiving responsibilities played an integral role by exposing them to images and realities that challenged long-standing beliefs and conceptions they held about their mother. In their reports daughters revealed how involvement in their mother's care placed them in settings that exacerbated their distress and contributed to their feeling overwhelmed and powerless to alleviate their mother's condition. In those instances where the mother had previously been otherwise healthy, the cancer diagnosis also marked the beginnings of first-time caregiving, bringing with it a marked role reversal. The significance of this life cycle turning point is noteworthy. For many daughters this represented an unprecedented behavioral shift in their relationship with their mother. As they were thrown into the unfamiliar role of giving support and encouragement to their mother, rather than being the recipient of such support, they found the experience challenging and emotionally distressing. Daughters needed to work through the significance of this development and deal with the implications of this life transition.

***Scope of careprovision.*** Daughters performed an array of caregiving tasks. These included attending doctors' appointments with their mothers, accompanying them to radiation treatments, obtaining medical information and completing insurance-related paperwork, fielding phone calls; helping with household activities such as errands and cooking; and helping with personal activities such as bathing. Many of the daughters were very matter-of-fact about their

caregiving, explaining that "I just did what I needed to do."

In the course of their caregiving, some daughters were involved in more hands-on caregiving, such as wound care. Thus, they were exposed to painful and uncomfortable aspects of the disease and its treatment. For them, this made the prospect of acquiring breast cancer all the more alarming. One daughter described her extensive care for her mother:

Well, in the beginning, when she just came back from the surgery, I needed to clean her and clean her drain, and just take care of her on a physical level, because she didn't want my brother or my father to see her. And that bothered me. I couldn't handle the incision, I couldn't handle all this — the blue and the black-and-blue colors — because I just don't deal with blood and all of that. ...So I sort of bit the bullet and did...and just did it.

***Increased protective and supportive behavior.*** As part of their careprovision, daughters reported an increase in behavior intended to be protective and supportive. They described a variety of actions that they engaged in to shield their mother from distress and spare her additional emotional pain. One type of behavior daughters frequently mentioned was the effort they took to keep hidden from their mother their worries and feelings about the cancer diagnosis and its ramifications. As one daughter confided, "I didn't want my mother to know that we were worried. Because, letting her know that, we probably increase her pain. We probably would scare her." Another daughter noted her efforts in this regard:

I only cried when my mother was not around . . . I don't know, just in my mind, I felt I needed to be strong for her. . .it just became that I had to be there for her and I had to support her, and I had to — I had to be the strong one.

These attempts to be protective and shield their mother from undue distress and worry were often achieved at some cost to the daughter. As the following account illustrates, this effort could require intense self-control and exert an emotional toll:

It took me a while for me to really come to terms with reality, that in reality that was cancer. . . . [T]he other problem that I had was, having to *deal* with that struggle, and, at the same time, having to present myself to my mother, as if it — as if nothing was happening. As if, "Oh, well, so what? We deal with it, it happens." Well, I was *burning* inside. I was suffering. But I could never let my mother know that I was worried, because, number one, I *knew* she was worried . . . and to me, it was a struggle, because I have to deal with my own anxiety, and, at the same time, I have to be able to show something different to my mother.

Daughters also felt that it was important to not let their mother become aware of the toll that caregiving was having on them. This practice added another layer of demand on the daughter. One daughter explained:

Thank God I had sufficient strength to be able to deal with the situation and that she never saw me down. I always tried to look strong in front of her.

**Caregiving burdens.** Daughters acknowledged that caring for their mother was a major commitment, but one that they would persist in doing. As one daughter related:

I knew it was a big task, but it was something that was very important to me to do. So I never let the job overwhelm me. I never let like looking at the mountain overwhelm me and not be able to climb it. You know, I just — I wouldn't let that feeling come.

Similarly, daughters who were impeded by life circumstances in providing the level of care and attention that they felt they should give their mothers, were distressed at the situation:

A couple of times I just took the day off to do it with her [radiation treatment appointments], but I just couldn't do it every day, so — I felt bad that I wasn't able to do that with her.

Daughters freely acknowledged the objective realities of the burdens that their careprovision imposed on their daily lives, but dismissed them because they were doing something important—caring for their mother. The daughters' narratives clearly illustrated how careprovision needed to be managed with a variety of other competing demands. This was a process that was not easy, but one that daughters accepted. As one young mother explained:

It only seems like a burden because, you know, when you have two kids and they're busy with sports and scouts and — I'm working full time, and teaching is a demanding job and it's like — it's like sometimes people say: "Just don't put anything else in my schedule." So it was never because I didn't *want* to do it. It was just another thing to do.

Another daughter stated:

I have a routine — usually after work, I go home. And I have my routine at home with my children and my family, but now that I had to go with my mother to the doctor, I had to change all that, and take her to the doctor and then go home sometimes, and get home late and — and everything was just a little bit more disruptive — my routine itself.

Daughters also admitted that there careprovision came at some personal costs. As one daughter stated:

It took a lot of time out of my schedule, making appointments for my mother, the medical bills I had to deal with, and alleviating my mother's anxieties *especially* depleted my energy.

This same daughter later admitted to an acute health event directly related to her involvement in caregiving: "In November 30<sup>th</sup>, I couldn't walk, suddenly. ...my back gave out."

***Careprovision competes with daughters' life cycle events.*** For a few of the daughters, their mother's illness and their need to be involved in her care and support came at a particularly trying time, during their pregnancies. Rather than their mothers being available for the daughters, to support them through this important life experience, the daughters had to be available to meet their mothers' needs. Clearly, even the fact that the attention of the family now shifted from them to their mothers was difficult to withstand. They felt that a time which they had anticipated as being special to them, with the focus of care on them and their upcoming child, was now directed toward their mother. The range of emotions and conflicts that the daughters were experiencing contributed to the stresses they encountered in their careprovision. As one daughter shared:

I was worried — I was sort of selfish in thinking that I was having the baby in October and I knew they wanted her to do treatment soon after, and was sort of thinking like, how will she be able to be in this with me, and I was really angry and feeling like we finally have a happy event and that it was marred by this diagnosis. So I felt really angry about that, that we couldn't just be happy. Like my mother couldn't just be happy. I couldn't just be happy. Like why couldn't we just focus on this happy event, that a baby was coming and it had to be — you know — just poisoned by the — as much as we tried for it not to be.

***Role reversal.*** Another lifecycle development precipitated by the cancer diagnosis was the reversal of roles that accompanied the assumption of caregiving activities. For many daughters, this represented a marked and unprecedented behavioral shift in their relationship with their mother. As one daughter succinctly stated, "There was a definite role reversal, where I would always look to her for support and now she looks to me for support. So, that was a big change." Daughters needed to work through the significance of this event and deal with the perceptual changes that this life transition represented. The emotions that this occurrence can engender are illustrated in the following narrative:

It was really weird for me, like my mother's always taking care of *me*. So like it was — at the very beginning stages of me taking care of her was very weird... . She was scared. And I don't know, I felt like I have to be strong for her. And I felt I had to like — I felt the roles reversed. I had to be comforting her. . . . My instincts were to be the kid, but I couldn't. . . . I feel I have a kid, to a certain extent, sometimes. Like my mother's my child, like I have these obligations to her.

A second daughter similarly remarked:

Oh, I was sad. Because we had been talking about this [daughter having a baby] for so long: you're going to come out, you'll come out the day before — because I had a

scheduled C-section, so we knew when I was going to give birth. So she was always going to come out a day or two before. And so I was upset. I didn't let her know that, but I was very saddened, because it was going to be exciting. We'd all go to the hospital together. ...I was — I was — I was sad and shocked that I had to rearrange these thoughts, but I came to terms with it, I think, rather quickly.

***Range of caregiving involvement: Domains with which daughter provided help.*** To fully comprehend the adverse consequences associated with caregiving necessitates an understanding of the caregiving situation, specifically the scope of the daughter's caregiving responsibilities. Using information collected from the caregiver daughter surveys we examined the scope of the daughter's caregiving responses. This assessment was based on daughters' reports of the patient's need for assistance and source of assistance on a variety of day-to-day activities. These activities group into one of seven activity domains:

- (1) Home Health activities, consisting of home medical care tasks, such as keeping track of medication, changing dressings, and maintaining special equipment;
- (2) Instrumental activities, which includes the tasks associated with maintaining a household, such as cooking, cleaning, and shopping;
- (3) Personal activities of daily living, consisting of tasks such as dressing, walking, bathing, and personal hygiene;
- (4) Transportation activities, which includes travel either to medical appointments or other purposes;
- (5) Administrative activities, which includes filling out insurance forms, banking tasks, and legal assistance;
- (6) Legal activities, consisting of illness-related legal counseling; and
- (7) Formal health care activities, including obtaining and coordinating the parent's formal health care.

Daughters provided aid to their mothers in a variety of domains. Overall, 93% of the daughters reported providing practical assistance to their parent in at least one of these activity domains. Approximately three-fourths (76%) of the daughters were assisting in three or more domains (see Table 20). Daughters were involved in helping their mothers with numerous tasks ( $M = 7.66$  tasks;  $SD = 3.6$ ). Seventy percent of the daughters helped their mothers with at least 6 tasks, with 22% helping with 11 or more. The most common areas were instrumental care (93%), transportation (93%), and administrative activities (91%) (see Table 20).

**Comparison of low-high perceived risk group on scope of careprovision.** There were no significant differences between daughters who perceived themselves at low risk for developing breast cancer and those who perceived themselves at high risk, with regard to the number of domains of providing help. However a greater percentage of daughters in the perceived high risk group provided help in specific domains. With regards with Home health activities, more daughters in the high risk group helped – 64% vs. 14%. Other research has suggested that exposure to wounds or scarring is associated with increased traumatic stress in at risk relatives. High risk daughters also were involved in more care tasks. Nearly half (46%) helped with at least 11 tasks compared to none of the low risk daughters. The mean number of care tasks was significantly greater for high risk group vs. the low risk group ( $M=9.0$ ,  $SD=3.2$  vs.  $M=5.7$ ,  $SD=2.7$ ). (see Table 22).

**Caregiving burden and strain.** Familial caregivers can experience myriad burdens associated with their caregiving. The constant concern to meet the parent's needs for assistance and support can engender stress. Social burdens can emerge as a result of restrictions on time and freedom imposed by having to assume the parent's responsibilities. Caregiving can disrupt personal routines, requiring the care provider to decrease time spent on social and leisure activities. It can also create potential role conflicts due to having to balance the needs of the sick family member with those of well members. Care provision can affect the caregiving daughter's ability to engage in and perform work effectively. It can cause her to miss work, reduce her work schedule, quit her job or even postpone starting a job. Chronic fatigue, physical exhaustion, and a deterioration in health are some of the physical burdens associated with the provision of care. Caregiving can impose financial burdens as well. Separate from the costs associated with the medical treatment and management of the illness, financial burdens represent the hidden costs associated with caregiving and encompass not only the out-of-pocket expenditures incurred in the care provision, but also the cost of lifestyle changes necessitated by providing care, such as a change in residence or frequent travel for care-related visits. This is in addition to the financial costs associated with lost work time and the health care costs arising from the physical burdens experienced by the caregiver.

The caregiving daughter is likely to be at a stage in the life cycle where she is experiencing multiple role demands arising from marital obligations, child-rearing responsibilities and work requirements. Such competing role demands can exacerbate the consequences of family care and are a potential source of strain, not only at work but in her relationships with other family members.

We examined five specific domains of burden -- social, time, physical, financial and employment, exploring the extent to which providing informal support and assistance to their ill mother has impacted adversely on the daughter's everyday life. We also explored the strains that caregiving imposed on the daughter's broader family system.

**Social burden.** Most of the caregiving daughters reported that their caregiving had

impacted on their social relationships. More than half (56%) of the daughters reported that their mother's illness reduced the amount of time spent with friends, neighbors and acquaintances, with 10% reporting that their time was reduced a great deal. Similarly, almost half (47%) reduced their outside activities (i.e., hobbies and vacations), with 12% reporting a great deal of reduction in these social activities. Sixty-nine percent of the daughters reported that their parent's illness had reduced their time to take care of their own household duties and tasks and more than half (55%) reported that their mother's illness had made it at least a little difficult to establish a daily routine and plan activities. Forty-four percent of the daughters felt that as a consequence of their mother's illness they had reduced the time they spent with other family members (see Table 24).

**Time burden.** Time burden is another caregiving consequence experienced as caregiving daughters accommodate their other responsibilities and duties in conjunction with their caregiving tasks. Over half (60%) of the daughters reported needing to cut down on their regular daily activities due to caregiving, 34% felt that they had accomplished less than they would like due to their caregiving, and 34% felt that they did not do their regular activities as carefully as usual (see Table 25).

**Physical burden.** Over half (60%) of the daughters reported at least a little physical strain (i.e., aches and pains) due to their caregiving, with 9% reporting a great deal of strain. Similarly, half of the daughters attributed a decline in energy for other household activities as a consequence of their caregiving, with 9% reporting a lot less energy (see Table 26).

**Financial burden.** Serious illness can have a profound impact on the patient's finances and this impact can also encompass the extended family. However, only a small number of the daughters were experiencing financial problems due to their involvement in their mother's illness. Nonetheless, 22% reported changes in their financial habits and lifestyle due to caregiving and 19% of the women reported passing up financial opportunities due to the illness (see Table 27).

**Employment burden.** Another consequence of caregiving is the problems it can engender for those daughters who are employed. For these daughters, 83% reported that their mother's illness affected their ability to concentrate on the job or do their best at work, 12% to a great extent. More than half (55%) of those employed also reported that they had left work early or come in late due to their caregiving, on average 3 times since their mother's diagnosis. Almost three-fourths (72%) of the daughters reported taking off days -- sick, vacation and personal time -- due to their caregiving, on average 3.7 days since their mother was diagnosed with cancer (see Table 28).

**Comparison of low perceived cancer risk group to high perceived cancer risk group on burden.** Low perceived risk daughters were compared to high perceived risk daughters with regard to the various types of burden. No significant differences between the groups was found

regarding time burden and financial burden (see Table 30, 32).

However, with regard to their social burden, a significant difference was found between the groups, such that whereas only 29% of the low perceived risk daughters reported that they had reduced the time spent with other family members, almost two-thirds (63%) of the high perceived risk daughters did so (see Table 29).

In addition, with regard to their physical burden, a significant difference was found between the groups, such that whereas only around a third (36%) of the low perceived risk daughters reported that they had experienced physical strain from caregiving since their mother's diagnosis, the majority (81%) of the high perceived risk daughters reported experiencing at least a little physical strain, with 18% experiencing a great deal of strain (see Table 31).

Among daughters who worked, low perceived risk daughters were compared to high perceived risk daughters with regard to employment burden. Significant differences were found between the groups, such that high-risk daughters were significantly more likely than low-risk daughters to take off days from work -- sick, vacation and personal time -- due to their caregiving (M = 3.12 days; SD = 1.13 versus M = 1.91 days; SD = 1.04).

***Daughters and mothers' appraisal of illness predictability.*** Both patients and daughter completed the Mishel Uncertainty in Illness Scale [Mishel, 1981], which assesses the perceived predictability of illness. For daughters, the mean score was 14.21 (SD = 3.85), with a possible range of 4-20, with higher scores indicative of less predictability. This indicates that daughters experienced the nature of their mother's illness as relatively unpredictable.

Seventy percent of the daughters somewhat or strongly disagreed that they knew when their mother was going to have a good or bad day, and somewhat or strongly disagreed that it was clear when their mother's illness was going to get better or worse. Regarding the overall course of their mother's illness, almost half (49%) agreed that they could generally predict its course, although 68% somewhat or strongly disagreed that their mother's distress was predictable (see Table 34).

For mothers, the mean score was 13.09 (SD = 3.44), with a possible range of 4-20, with higher scores indicative of less predictability. This indicates that mothers also experienced the nature of their illness as relatively unpredictable.

With regard to whether they knew when they were going to have a good or bad day, mothers' responses were mixed. Whereas 50% somewhat or strongly agreed with this statement, 40% somewhat or strongly disagreed. More than half (54%) somewhat or strongly disagreed that they could generally predict the course of the illness. However, approximately two-thirds of the mothers (66%) somewhat or strongly agreed that it was clear to them when their illness was

getting better or worse and more than half (54%) somewhat or strongly agreed that their physical distress was predictable (see Table 35).

***Comparison of low perceived cancer risk group to high perceived cancer risk group on illness predictability.*** Low-risk daughters were compared to high-risk daughters with regard to their appraisal of illness predictability. The measure has a possible range of 4-20, with higher scores indicative of less predictability. There was a significant difference between the groups, such that the high-risk daughters had significantly higher mean scores ( $M = 16.09$ ,  $SD = 1.87$ ) than the low-risk daughters ( $M = 12.71$ ,  $SD = 3.54$ ), indicating that the high-risk daughters experienced a greater lack of predictability regarding their mother's illness.

There were no significant differences between the groups with regard to any of the individual items (see Table 36).

***Daughters' and mothers' appraisal of personal control over mother's illness.*** Both daughters and mothers completed a measure of perceived personal control over the illness [Affleck et al., 1987]. The daughters' mean score was 3.65 ( $SD = .75$ ), with a possible range of 1-5, with higher scores indicative of less personal control. This indicates that daughters felt they had relatively little control over their mother's illness.

Specifically, regarding their mother's fatigue, 59% of the daughters reported very little or no control. Similarly, regarding their mother's day-to-day discomfort, 62% of the daughters reported very little or no control. Sixty-five percent reported very little or no personal control over their mother's day-to-day amount of pain and almost three-fourths (71%) of the daughters reported very little or no personal control over the long-term course of their mother's illness.

In contrast, almost half of the daughters (46%) reported that they had either quite a bit or an extreme amount of personal control over the medical care and treatment of their mother's illness. (See Table 37)

The mothers' mean score was 2.20 ( $SD = .72$ ). This indicates that they felt, relative to the daughters' report, more in control over their own illness.

Specifically, regarding their mother's fatigue, 36% reported quite a bit or an extreme amount of control. Similarly, regarding their day-to-day discomfort, 42% reported quite a bit or an extreme amount of control. Twenty-eight percent reported quite a bit or an extreme amount of control over their day-to-day pain and 38% reported quite a bit or an extreme amount of personal control over the long-term course of their illness. Mothers also reported a greater amount of control over their medical care and treatment – 68% reported quite a bit or an extreme amount of control. (See Table 38).

***Comparison of low perceived cancer risk group to high perceived cancer risk group on***

**personal control over illness.** Low-risk daughters were compared to high-risk daughters with regard to their appraisal of personal control over their mother's illness. There were no significant differences between the groups with regard to the overall measure or any of the individual items (see Table 39).

**Exploration of Risk Profile for Caregiver Distress (Technical 4).** In addition to cancer affecting the patients themselves, its diagnosis, treatment, and resolution affect their family members as well, the "second-order patients" [Rait and Lederberg, 1989]. Investigations have documented high levels of emotional and psychological distress among family members of cancer patients [Harrison et al., 1995; Raveis et al., 1998; Toseland et al., 1995], sometimes to an even greater extent than the patients themselves [Keitel et al., 1990; Kornblith et al., 1994; Northouse et al., 2000].

Yet, our understanding of the various ways in which cancer impacts upon the family is still evolving. It has been suggested that as family members learn of their loved one's diagnosis and process its implications they experience a period of crisis fraught with severe emotional distress and life/death concerns [Veach and Nicholas, 1998] that parallels the "existential plight" patients encounter in the initial months following the diagnosis [Weisman and Worden, 1976-1977]. Indeed, studies have documented a range of emotional responses to a relative's cancer diagnosis, including shock and numbness; disbelief and denial; panic, desperation, confusion, and fear; helplessness, frustration, and guilt; and a combination of worry and sadness [Leedham and Meyerowitz, 1999; Northouse, 1984, 1991; Tarkan, 1999].

In studies of women with a family history of breast cancer, Lerman et al. [1993, 1994] found that one-third of the women reported breast cancer worry that impaired their daily functioning and 53% experienced intrusive thoughts about breast cancer. The women reported levels of intrusive thoughts that were comparable to those seen in clinical populations that included individuals exposed to a traumatic stressor. This preoccupation with the disease may be particularly exacerbated for women who were caregivers for their mothers during their illness. Erblich et al. (2000) found in their study of women with family histories of breast cancer that those who had cared for their mothers with breast cancer reported higher levels of breast cancer-specific distress (i.e., intrusive thoughts and avoidance) than those who had not. The experience of seeing first-hand the difficulties related to their mother's breast cancer experience may impact the daughters' sense of personal risk and increase the concerns they associate with the disease. Wellisch, Schains, Gritz, & Wang (1996) found that the majority of the daughters (72%) had viewed the site of their mothers' surgery and that daughters perceived their mothers' quality life as significantly lowered post-surgery, especially in areas related to their attractiveness and sexuality.

The daughters' narrative accounts document that the diagnosis of cancer is an event of significant import to family functioning and demonstrate that patients' family members also undergo a period of crisis and existential plight. The daughters reported experiencing a broad

range of intense emotional responses upon learning of their mother's breast cancer diagnosis and assimilating its implications. Some of these emotions were short-lived, such as the shock and disbelief they encountered. The impact of other responses, such as panic, fear, distress and sadness, were more long-lasting. The daughters' accounts documented the traumatic nature of the diagnosis and provided compelling examples of how subsequent occurrences or circumstances triggered strong emotional memories about the event.

**Shock.** Chief among the initial responses that daughters reported experiencing was shock. Their reports dramatically documented the intensity with which they recalled being hit with the news of their mother's breast cancer diagnosis. As one daughter recounted in a statement that was typical of this experience: "I was in shock. ...And you're — you — I was in such a state of shock that you don't — you freeze, and you don't know what to do." For some, the shock they encountered was precipitated by a lack of forewarning:

It was a shock. I — my heart started racing and — because she started crying as she was telling me. So that kind of — I got very upset. I was crying, I was breathing heavily; I remember I was hyperventilating. It just came out of left field. I had no idea. . . . And it just — it was just a complete shock. It was like I got cold-cocked in the face.

Similarly, another daughter recounted how the shock she felt was due to a complete lack of awareness that anyone in their family could be at risk for cancer: "I was surprised. I was shocked. I was — I just, you know, that word, that "C" word, I just didn't — we had never had it in our family before, so I was a little, well, "How could that be?"

**Disbelief.** Closely following the initial shock daughters experienced upon learning the news was a range of other emotions, such as disbelief, panic, and fear. The surprise and lack of forewarning about the event contributed to some daughters having a difficult time accepting the diagnosis and initially reacting to the news with disbelief. As one daughter recalled:

Well, at first, I was in, in denial. I just didn't want to — a lot of things were going through my mind. . . it took me a while for me to really come to terms with reality, that in reality that was cancer.

Echoed another -- "[E]ven though the doctors are saying all this. . . you kind of don't *believe* it." Some daughters found it hard to accept that this was actually happening to them.

Part of the incredulity associated with the event was their absence of prior exposure to such issues. They found themselves faced with a situation that they knew happened to others, but not to them:

And I just was thinking like: this *cannot* be my life. But I won't — I don't *believe* this. It was such shock and disbelief, like — it is not like my life has — like I have friends who

like every day there's something else. That her grandmother had a heart attack and her this and that. No, that's not my life. I don't know from these traumas. I don't know from these horrible mishaps. You know? Like I don't know from bad things much.

In the wake of their "shattered assumptions" of safety [Janoff-Bulman, 1992] and their realization that their family was not immune or protected from health threats, some daughters reported feeling panicked and fearful.

**Panic.** The daughters' accounts documented that in some instances the panic they experienced upon learning the diagnosis was so intense that it momentarily immobilized them from taking any purposeful action. As one daughter vividly recounted, "[Y]ou're panicky; you're splattered — your head is splattered all over; your thoughts are jumping — and you don't know what direction to go into, you're just *wild*."

The daughters' description of their feelings revealed that the panic and desperation they felt emanated from a deep-rooted concern for their mother's well-being. This consideration is clearly evident in the following description provided by a daughter recalling the panic she felt upon hearing about her mother's breast cancer diagnosis and the frenzy of activity that ensued:

I would say just panic, and just — desperation — I just started trying to call anybody who I knew who had a wife, a mother, or somebody, to just try to find out as much as I could, to try to help her.

**Fear.** Fear was another common response to learning of their mother's cancer diagnosis. Cancer can be a life-threatening illness. The daughters' accounts of their initial response when they heard the news illustrate that this information evoked an instinctual reaction that raised fears and worries about their mother's survival:

I was just scared and terrified . . . I didn't know a lot about it because I hadn't spoken to my parents yet. How advanced was the cancer? I just — all these thoughts were running through my head. So I was just kind of going off the deep end. I didn't know how advanced it was, and I just — I just wanted to know that she was okay, that she was going to be okay, and no one could answer that for me. You know, it was just — it was scary.

Similarly, another daughter disclosed: "I was just so scared. So scared. I don't know, it's just a — so many feelings at the same time — I got so scared . . . lots of things go through your head. And they're not the greatest."

Although the initial concerns that daughters felt upon learning of their mother's diagnosis usually diminished gradually, for some these fears and worries have endured. As one daughter noted:

I still — to this day — if someone would tell me she will be a hundred percent fine, which I don't know if they ever will, I'm going to be scared for her life. I'm going to be scared for her health and I'll be scared of something happening.

**Overwhelmed.** Several of the daughters found it extraordinarily difficult to deal with their mother's diagnosis and recalled being extremely distressed and demoralized following the event. In their narratives they recounted how it was almost more than they could bear. They recalled that they felt very drained and were unable to function. Said one daughter, "I completely fell apart. . . . I was in complete tears and I had that *pit* in my stomach, and it was just a horrible horrible feeling." Another recalled, "[A]t that period of time, I was crying so much at home, and I just felt like every time my husband saw me, I was a mess." In some instances the daughters' distress was so severe that it impacted their ability to relate to other people, as this daughter's account illustrates:

In the beginning, when it just happened, I couldn't deal with it. I didn't want to talk to anyone, I just wanted to lay in my bed. Like people would come to my house, I would just close them out.

For these women the event was traumatizing. Not only was their initial distress and demoralization intense, but the upset surrounding this event was so strong that subsequent events or circumstances continued to re-awaken these emotional memories. As one daughter articulated:

[W]e didn't have phone service, and I'll never forget having a cell phone for about a week, and trying to call doctors and get information, and to this day, when I hear that ring, I like jump through the ceiling. We actually changed the ring on the phone, because I can't — you know, . . . if I hear that tone, it just hits me — it just brings me back.

**Sadness.** Although sadness was another persistent emotional response that daughters reported, it generally emerged over time, once the initial emotional responses abated or receded in intensity. Daughters found it very difficult to see their mothers in this situation and it saddened them. Said one daughter, "I felt very sad. Very sad for her, very pained by the whole thing." The sadness daughters experienced was very pervasive and enduring. One daughter commented that: "I must have cried for days."

Daughters' sadness often accompanied their feeling helpless to remedy the situation. As one daughter shared: "There was really nothing I could do to help her. You sort of feel helpless. . . . I felt very bad for her. I was sad." Another daughter's comments illustrate that these feelings were pervasive and shared by the family:

Well, when my mother was diagnosed with cancer all of us, her children and whole family thought that the world had ended because it was a very big thing for us . . . . How

should I say it? It's a very sad thing when your mother is diagnosed with cancer.

***Illness Representations in Daughters of Women with Breast Cancer.*** Rees et al (2001) have theorized, first-hand experience with breast cancer in a family member has the potential to impact illness representations. Leventhal et al. (2001) has identified five key elements around which the representation of illness and treatment is organized: the *identity* of the threat, the *time line*, the perceived *cause* of the disease, its *consequences*, and *controllability*. These attributes of illness representation define the objective problem and delineate goals or targets for coping. In turn, the effectiveness of coping is appraised in light of these targets. Understanding how caregiving daughters view various aspects of their mother's illness experience and the attendant consequences will help inform services to this vulnerable population.

From a content analysis of the daughters' qualitative interviews, we discerned six themes that speak to the "identity" of the illness experience, i.e., nature and characteristics of the illness experience: Breast cancer can represent a difficult challenge for the patient to deal with; breast cancer can represent a challenge that can be endured; the treatment/hospital experience can be unpleasant; the treatment/hospital experience can be pleasant; aspects of the illness situation can be traumatic for family members; and sometimes breast cancer is manageable for the family. Under the "consequences" aspect of daughters' breast cancer illness representation, six themes emerged from the data that speak to the effects of the illness experience: breast cancer can exact an emotional toll from family members; family members can become preoccupied with the illness; breast cancer can place a burden on family members; breast cancer can complicate relationships between the patient and family members; breast cancer can engender dissension among family members; family members can experience an increased sense of personal vulnerability; and family members can become concerned about passing on the risk to children; and there can be positive consequences to breast cancer. These are described more fully below.

*Breast cancer can represent a difficult challenge for the patient to deal with.* For some women, the diagnosis of breast cancer is overwhelming. Explained one daughter:

[My mother is] angry at having cancer. My mother felt that the cancer totally derailed her life. And that she felt – and she's said this to me, . . . The train has left the station." – These are my mother's words – "the train has left the station, and I'm still on the platform." ...[T]his totally stopped her life dead in its tracks. And she just couldn't go on and be the person that she always was.

A daughter who is witness to this type of response to breast cancer may identify the illness as devastating and insurmountable.

*Breast cancer can represent a challenge that can be endured..* Several daughters noted that their mothers' responses indicate that whereas dealing with breast cancer can be difficult, it is nevertheless a challenge that can be overcome. As one daughter related:

You see, since she's been the kind of patient that has taken this in a positive way...my mother was the one who oriented us. I would say because we were all very disoriented in the way that we thought immediately cancer. She was not. She was sad, I have to say, but not like us. She took it very positive. She sat down and talked to all of us and told us, no, you can't get like that because you don't know. So we wanted to...we were sad, but we were also thinking that she was giving us the courage that we didn't have.

Another daughter described her mother as committed to not giving in to the disease:

Mom's going to be fine, and she's a fighter, and she's got a great attitude — and I think attitude is a big thing, you know? and she — she never sat and felt depressed and felt, you know, oh, sorry for herself. She decided that she was going to fight this, and she was going to move on with her life, and go on. And that's exactly how she did. She played tennis and she was active and she just never let it stop her.

*The treatment/hospital experience can be unpleasant.* Another contrast was noted in the ways that daughters characterized their mother's treatment experience. A daughter's identification of the illness experience can be informed by her perception of her mother's experiences with the health care profession (e.g., physicians and hospital personnel). Medical personnel can subsequently be viewed as either another part of the problem, or, contrastingly, as allies in the fight against the disease. In some cases, daughters were privy to very unpleasant circumstances. As one daughter described:

It — I was really — it was just not a good experience with the health professionals, with the caregivers. And they — they weren't around to help my mother, *either*, really. I mean, her drain needed to be emptied and nobody came around to empty it, and I had to go to the desk and say: My mother's drain needs to be emptied, it's almost full. And they'd say: Okay, we'll be right there. And nobody would come. And the first night she was there, her, her call light didn't work — unbeknownst to us. And she would put the call light on for pain medicine and no one would come. Finally, she went out — she took — she went out to the nurses' station, with the I.V. pole — this is the *day* of surgery — to get pain medicine — in the middle of the night. Finally, we realized that it was the call light that wasn't working. So it was pretty — it was pretty emotionally traumatic.

Another daughter similarly recounted her disappointment with her mother's physician:

But when I met with the doctor, he was really very dry. He was very indifferent. He was very — businesslike type. And, you know, we really didn't like that. And Dr. [Name] reassured me he was a good doctor. I said, He may be a good doctor, but I feel that there are different areas for different people to — to pursue. And he has to understand that when people come here with cancer, this is a serious matter; he should be a little bit more — humane. You know, in a human style. And maybe — I don't know. I mean, he's not a

social worker, whatever, but — you know, be a little bit more compassionate. He wasn't.

*The treatment/hospital experience can be pleasant.* In contrast, other daughters attested to satisfying interchanges with the medical community. Such perceptions are significant, as they are often filed away, and referred to if/when one is faced with similar medical circumstances in the future. One daughter recounted a particularly rewarding experience with her mother's care team:

It was something that I didn't even feel like they were doctors. They were more like friends. The doctor who operated was also a person who committed himself to her case. I'm very grateful to him because he treated her as if he was her son, and everything went...even after the operation, we went back to visit him. He gave her a lot of trust. It was a wonderful thing. I never thought it would be....aside from suffering a lot, they always gave us courage. They always gave us hope, and it was something dignified of letting it in the doctor's hands and the medicine. All of them are very capable.

*Aspects of the illness situation can be traumatic for family members.* For several daughters, their mother's circumstances were perceived as traumatic and the effects longstanding:

...[W]e didn't have phone service, and I'll never forget having a cell phone for about a week, and trying to call doctors and get information, and to this day, when I hear that ring, I like jump through the ceiling. We actually changed the ring on the phone, because I can't — you know, ... if I hear that tone, it just hits me — it just brings me back.

*Sometimes breast cancer is manageable for the family.* This sense of trauma is not always the case. For some family members, the breast cancer situation is more manageable, generally when the progression of the disease was more contained:

[I]t really hasn't really changed our lives that drastically, because I'm sure if her breast cancer was more serious, and she needed more treatments, and we were a little more uncertain of the prognosis, it would have, you know, been a lot different. It would have changed our lives, probably, a lot more.

*Breast cancer can exact an emotional toll from family members.* Many of the daughters reported that they and other family members were emotionally drained from dealing with the mother's breast cancer. As one daughter articulated, regarding her own situation, "...[Y]ou're panicky; you're splattered — your head is splattered all over; your thoughts are jumping — and you don't know what direction to go into, you're just *wild*. Another daughter recalled, "Because, at that period of time, I was crying so much at home, and I just felt like every time my husband saw me, I was a mess." One daughter described her father's precarious emotional state:

[W]hat'll happen is one of two things. Either he will — he'll get very...dissociated and spacy, and you know, sort of lose his keys and not be able to just identify what he's feeling. But the other extreme is, he gets very weepy and very vulnerable, and scared, and, to be frank, that's a har — that's a very hard place for me to see him in.

Such recollections can prompt daughters to characterize breast cancer as an experience that is costly for the family.

*Family members can become preoccupied with the illness.* Even when emotional states become more stable, family members can remain preoccupied with the illness experience; it is constantly on their minds. One daughter related:

It's [mother's breast cancer] always like there. And sometimes I find myself cooking something, and I can't see the TV but I can hear it. And then... and I'll start crying. And I'm not even looking at the TV because where I'm at I can't see it. I just like hear *something*, and it will set it off.

Another daughter shared, "I was extremely preoccupied. ...Before I used to go out and enjoyed myself a lot. Now when I go out I feel preoccupied all the time, worry. " Echoed a third, "...[I]t's been really, you know, it's been occupying a lot of my emotional energy and thoughts..."

*Breast cancer can place a burden on family members.* Caregiving daughters may be especially aware of the burden that dealing with breast cancer can engender. Recalling her own caregiving involvement, one daughter confessed, "Well, it was very difficult because between my work, my home and also taking care of her, it was very....it wasn't easy..."

It was often difficult for daughters to incorporate their caregiving into their lives, given their other responsibilities. One daughter explained, "Sometimes I just felt like everything I was trying to juggle was overwhelming." Another elaborated in greater detail:

I think the first few months it impacted a great deal from the amount of time I spent with friends, amount sleep, amount of leisure. I feel like every waking moment was either work or care. Whether by phone or in person, it was exhausting. It was exhausting and I was drained...

*Breast cancer can complicate relationships between the patient and family members.* Many daughters experience the mother/daughter relationship as radically altered. For some, there has been a role reversal in the relationship. As one daughter shared, "I think, certainly there was a period in which everything was topsy turvy. Mothers were kids and kids were mothers, and — you know?" Not every daughter is comfortable with this change in roles. As another daughter explained, "And because I do still depend on her in so many other ways, that it's hard for me to suddenly step up to this new role that she's never asked of me before."

In addition, for some daughters, paradoxically, although their level of intimacy may increase as a function of the caregiving experience, a sense of distance may be introduced into their relationship with their mother, because they feel that they must protect her from any bad emotions. Because her illness has rendered her more vulnerable, daughters may feel less able to be completely open about their concerns. One daughter pointed out,

It's hard to get annoyed at your mother, when she has had breast cancer. She's still your *mother*, even though she has breast cancer – it's still your mother. You want to get annoyed, but you feel bad because she has breast cancer.

*Breast cancer can engender dissension among family members.* Several daughters recounted that the illness situation created stress in their relationship with other family members. This was often due to underlying resentment that other family members were not being as helpful as they could be with illness-related responsibilities. As one daughter expressed:

Like, right now, my sister is on vacation. She took like a month-and-a-half vacation. And it was in the middle of my mother — chemo. No. Chemo, no — radiation. And she calls once in a while, but she didn't say, Okay, I'm going to come back — I'm also having vacation; I'm going to give you a break, as you're working — because I'm working during the — I'm supposed to be on vacation, but I had to make up for the money I couldn't make during the whole time that I had to be with her, so — now I'm working to see how much I can catch up. And pay the bills; I'm paying the schools, and my kids, and this and that. And she's having vacation, and she went to have a vacation out in the country, and — and that really annoys me a little.

Other times dissension was a result of disagreement regarding about medical protocol.

I had to disagree with a lot of family members about — but that's okay. And that's hard too, because you're trying to find out about a disease, and, and also you're getting the input from everybody else, and their thoughts — but meanwhile, they're not *doing* the footwork.

*Family members can experience an increased sense of personal vulnerability.* The caregiving daughters in the sample talked about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability. These daughters recalled that prior to their mother's diagnosis they had not given much thought to the threat of breast cancer. That changed as this event destroyed any beliefs they may have previously held about immunity from cancer. As one daughter observed, "[I]f it happened to her, it can happen to me." Their new status as a woman with a family history of breast cancer also contributed to some daughters' sense of vulnerability. Commenting on this process, one daughter related: "[Y]ou know, beforehand I felt I had no risk whatsoever. And now, with this, I feel I am much — I am at a higher risk, given my history." As another daughter noted:

I think one of the most dominating issues that I had to deal with this time, because of my age, at this point — I'm older, and what's more of a reality for me is: *This can happen to me.*

*Family members can become concerned about passing on the risk to children.* Their mother's illness also impacts how some caregiving daughters' feel about their family's vulnerability to cancer. As with their own sense of heightened vulnerability, daughters' need to deal with their realization that this risk can impact future generations. As one daughter explained: "I think about my daughter too. Before this I never thought about it; not my mother, nor my daughter, never." Daughters' accounts indicate that their concerns for their daughter's health are more intense than their fears for their own risk status:

Just as I've become more concerned for myself, I've become more concerned for her. ...You know, because — that's one of the main risk factors is, you know, family history."

*There can be positive consequences to breast cancer.* Daughters were also able to discern some possible consequences emerging from their caregiving experiences. As one daughter expressed it, caregiving presented the opportunity for personal growth:

But it's been *very* good for me to be able to do these things for her, and show her that I *can* do things for her. Feel like a useful part. ...This has been a *positive* experience for me, and — in the final analysis.

Similarly, another positive benefit was the knowledge gained:

So now I think that in another situation...if it happens to me or to another family member or one of my children, then now I think I'll be able to deal with another situation. It's very informative because you never take the information because you're not in that situation, but now I think that it's something that has made me very capable.

***Caregiver levels of psychological distress.*** There has been an increasing awareness of the importance of understanding the broad range of psychological consequences associated with familial caregiving. The survey completed by the caregiving daughter included measures of depressive symptomatology and anxiety. The caregiving daughters' mean level of depressive symptomatology was 8.29 (SD = 7.63). Twelve percent reported a level of depressive symptomatology at or above the cut-off for a definition of probable caseness of clinical depression.

There has been an increasing awareness of the importance of understanding the broad range of psychological consequences associated with familial caregiving, beyond depressive

symptomatology. We included a second indicator of poor psychological functioning that has not been commonly studied in caregiving investigation -- state anxiety (i.e., a transitory emotional reaction to tension and apprehension often associated with the occurrence of a stressful event). We assessed caregiving daughters' level of state anxiety with the State Anxiety Scale of the State-Trait Anxiety Inventory (STAI-S). The STAI-S is a widely used measure of state anxiety. The mean of the caregiving daughter's scores on the state anxiety scale ( $M = 34.72$ ,  $SD = 12.18$ ).

***Comparison of low perceived cancer risk group to high perceived cancer risk group on psychological well-being.*** Daughters who perceived themselves at low risk for developing breast cancer were compared to those who perceived themselves at high risk, with regard to psychological well-being. No significant differences between the groups were found with regard to their levels of depression, the percentage of daughters at or above the cutoff for possible caseness, and their levels of anxiety (see Table 41).

***Correlates of depression and anxiety for daughters by potential risk factors.*** Depression and anxiety in caregiving daughters were examined, in terms of their relationships with potential risk factors (see Table 42). These are grouped into: patient/disease characteristics, daughter sociodemographics, daughters' relationships with their mothers prior to the illness and since the diagnosis, caregiving burden, impact of illness on the daughter and psychological distress.

***Patient/disease characteristics:*** The extent of the cancer was significantly correlated with both depression and anxiety in daughters, such that daughters of patients with non-localized cancer were significantly more depressed and anxious. In addition, daughters of patients who had received a combination of surgery, radiation, and chemotherapy were significantly more depressed.

***Daughter sociodemographics:*** Daughters who were married were significantly less depressed and anxious, those with higher levels of education were significantly less depressed, and those with a greater number of children were significantly less anxious.

***Daughters' relationships with their mothers prior to the illness:*** Daughters who reported a higher level of conflict prior to the illness were significantly more depressed and anxious. In keeping with this, daughters who were more satisfied with their relationship with their mother were significantly less depressed and anxious, and daughters who felt more admired by their mother were significantly less depressed and anxious as well.

***Daughters' relationships with their mothers since the illness:*** Daughters who reported a higher level of satisfaction with their relationship with their mother since the illness were significantly less depressed and anxious, and daughters who felt more admired by their mother were less significantly depressed.

***Caregiving burden:*** Daughters who provided more help with legal activities were

significantly more depressed and anxious.

*Illness predictability:* Daughters who reported higher levels of uncertainty (i.e., experienced their mother's illness as less predictable) were significantly less depressed.

*Impact of the illness on the daughter:* Daughters with higher scores on the overall scale reported significantly greater levels of depression and anxiety. Specifically, daughters who reported a greater extent of intrusiveness of thoughts and feelings about their mother's breast cancer were significantly more depressed and anxious, and those who reported a higher frequency of efforts to avoid thoughts or feelings about the illness were significantly more depressed and anxious as well.

*Daughter's psychological well-being:* Daughters who were more depressed were significantly more anxious. Specifically, daughters scoring higher on the depressive affect subscale, the somatic/vegetative subscale, and the interpersonal distress subscale; and scoring lower on the positive affect subscale, were significantly more anxious.

**Depression and anxiety in caregiving daughters by types of burden.** We next examined the levels of depression and anxiety in caregiving daughters in terms of the types of caregiving burden (see Table 43). With regard to social burden, those daughters who reported that their mother's illness had reduced to a great extent the amount of time they spent with friends, neighbors and acquaintances were significantly more anxious.

In addition, with regard to employment burden, daughters who took off days from work due to their caregiving duties 1-2 times were significantly less anxious. With regard to financial burden, daughters who reported that their financial problems due to their mother's illness were not very serious were significantly more depressed.

**Comparisons of daughters' depressive symptomatology by sociodemographics.** Caregiving daughters who were below the cut-off point for caseness for depression on the CES-D were compared with those above the cut-off, with regard to sociodemographics (see Table 44). There were no significant differences between the groups on most sociodemographic variables. However, daughters whose mothers had nonlocalized cancer were significantly more likely to have scores above the cut-off for depression.

**Comparisons of daughters' depressive symptomatology by changes in the mother/daughter relationship.** Caregiving daughters who were below the cut-off point for caseness for depression on the CES-D were compared with those above the cut-off, with regard to changes in the mother/daughter relationship (see Table 45). There were no significant differences between the group with regard to the Conflict, Satisfaction, Intimacy, and Relative Power subscales.

However, with regard to the Nurturance subscale (which assesses the extent to which daughters nurtured their mothers), a significant difference was found between the groups, such that a greater percentage of daughters who were not depressed reported that the relationship had changed in the direction of the daughters nurturing their mothers more since the illness than they did prior to the illness.

With regard to the Admiration subscale (which assesses the extent to which the daughters felt admired by their mothers), a significant difference was found between the groups, such that a greater percentage of daughters who were depressed reported that the extent to which they are treated like they are good at many things had changed for the worse since the illness.

***Comparisons of daughters' depressive symptomatology by burden.*** Caregiving daughters who were below the cut-off point for caseness for depression on the CES-D were compared with those above the cut-off, with regard to types of caregiving burden (see Table 46). With regard to social burden, time burden, physical burden, and employment burden there were no significant differences between the groups. However, with regard to financial burden, a significant difference was found, such that only daughters who were above the cut-off for depression reported very serious financial problems due to their mother's illness.

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#### **IV. Key Research Accomplishments**

- Daughters caring for a mother with breast cancer represent a vulnerable population.
- Careprovision provides daughters with an intimate knowledge of their mother's breast cancer experience.
- A mother's cancer diagnosis subjects adult daughters to existential plight, paralleling the severe emotional distress and life and death concerns patients encounter after a cancer diagnosis and initiating treatment.
- Daughters are confronted with having to integrate their emotional reactions to their mother's illness while simultaneously processing concerns about their own personal cancer susceptibility.
- Their mother's illness prompted recognition of increased family risk, rendered daughters with a heightened sense of personal vulnerability and raised concerns for future generations.
- Accounts also delineated how their involvement in their mother's illness precipitated a re-definition of daughters' personal values and altered their perceived future.
- Daughters' narrative accounts demonstrate that their mother's illness intensified their bond with their mother, while also presenting challenges in their relationship.
- Daughters performed a range of careprovision tasks that needed to be balanced with the demands of their daily lives.
- Careprovision initiated a number of relationship changes that impacted the quality of the mother-daughter relationship.
- Daughters needed to cope with the role reversal that their careprovision instigated.
- Narrative accounts reaffirm the necessity for clinicians need to appreciate the extent to which daughters can be impacted by their mother's cancer experience.

## **V. Reportable Outcomes**

### **Conference presentations:**

Raveis, V.H., "Psychosocial Concerns experienced by caregiving daughters." Poster presented at the Era of Hope, Department of Defense Breast Cancer Research Meeting, Orlando, FL., September 2002.

Raveis, V. H., "Aging Families and Breast Cancer." Podium presentation at the Annual Meeting of the American Public Health Association, Philadelphia, PA, November 2002.

Raveis, V. H., Pretter, S., Sapienza, T., Carrero, M., & Gregory, A., "Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships." Podium presentation at the Annual Meeting of the Gerontological Society of America, Boston, MA., November 2002.

Raveis, V.H., Pretter, S, Carrero, M, Sapienza, T "Breast Cancer and the Aging Family: Psychosocial Issues and Challenges Facing Adult Daughters." Podium presentation at the First Annual Conference the American Psychosocial Oncology Society (APOS), Orlando, FL, January-February 2004.

Raveis, V.H., Pretter, S., Sapienza, T., Carrero, M., "Psychosocial Issues at-risk women encounter in the provision of care to a relative with breast cancer." Podium presentation to be presented at the Annual Meeting of the American Public Health Association , Washington, D.C., November 2004.

### **Publications:**

Raveis, VH, Pretter, S, Carrero, M, Sapienza, T (2004) "Breast Cancer and the Aging Family: Psychosocial Issues and Challenges Facing Adult Daughters." *Psycho-Oncology*, 13: S7.

Raveis, VH, Pretter, S (2004 – In press) "Existential Plight of Adult Daughters Following Their Mother's Breast Cancer Diagnosis", *Psycho-Oncology*, 12.

### **Advisory committees:**

Dr. Raveis is a member of the Advisory Group on Cancer Survivorship and the Family, National Institute of Cancer, Office of Cancer Communications.

This national advisory group, convened by National Cancer Institute's Cancer Information Service, to develop evidence-based materials for NCI's *Facing Forward* series that addresses the challenges families face post-cancer treatment. Dr. Raveis is advising on the range of issues adult children may experience during their parent's survivorship period and providing approaches for coping with these issues.

Dr. Raveis is a member of the Cancer Expert Panel, Johnson & Johnson/Rosalynn Carter Institute Caregivers Program, Atlanta, Georgia

This is a national panel of experts, convened by the Rosalynn Carter Institute for Human Development, to share insights on careprovision in cancer.

**Grants:**

PI: Dr. Raveis

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Overall research aim is to understand the psychosocial needs and concerns of families affected by breast cancer, specifically to explore the psychological stresses and challenges familial caregivers (mothers, siblings) experience caring for a first degree relative with breast cancer. Study will: examine how caregiving may contribute to their perception of cancer risk; explore perceived cancer risk affects the quality of careprovision and the stresses and burdens they experience as a caregiver; and assemble information to inform educational and supportive interventions targeting families' psychosocial and assistance needs.

We also discerned in the daughters' narrative accounts that their reports of their cancer experience frequently included a discussion of other relatives -- siblings, aunts, and grandmothers who were diagnosed with breast cancer. We became aware in screening for the present investigation that a number of women reported a first degree female relative caregiver who was not their daughter. We realized that a comprehensive exploration of issues experienced by caregivers at increased risk of breast cancer due to familial risk would needed to examine this situation in other groups of women, in addition to adult daughters, although adult daughters are the most commonly impacted group. A subsequent grant was obtained from the Empire fund. This is permitting the collection of data from caregiving mothers and sisters.

## VI. Conclusions

**Summary.** With a continuing shift of cancer care to community-based care, there is a growing need to understand the costs to the family of the cancer experience. Such information is needed to inform programs that will enable family members, particularly adult daughters, who themselves may be at increased risk for breast cancer, to meet elderly cancer patients' needs for emotional support and practical assistance is paramount. Daughters lacking support themselves may have difficulty dealing with their own exaggerated fears and perceptions of personal cancer risk associated with their mother's disease. This in turn may adversely impact on their relationship with their mothers and impair their ability to provide their mothers with the support and assistance they require. Unsupportive network interchanges can detrimentally impact patients' psychological well-being. It may also impact physical recovery and survival. Cancer is a disease that impacts or affects the family unit, not just the patient. Programs and services need to target the family and support not only the patient but the special needs of family members. While family members may be regarded as part of the care team, they are also affected by the cancer experience. It needs to be more commonly acknowledged/recognized that they hold this dual status.

This study's overall research aim was to obtain exploratory, descriptive information that will increase understanding of the psychosocial needs and concerns of families affected by breast cancer, specifically, the issues experienced by adult daughter caregivers. The insights gained from this exploratory investigation are contributing to the knowledge base in this significant but understudied area. Such information is a necessary first step toward addressing the issues associated with the impact and consequences of cancer care on family caregivers and developing appropriate interventions based on these issues

.It is important to consider the family's response to the cancer diagnosis, as the reaction of family members to a patient's illness can influence the adjustment of the patient to the illness and impact upon the family's involvement in care provision . The information obtained from this investigation may aid clinicians in counseling or supporting family members dealing with the cancer diagnosis of a loved one. By focusing on the adult caregiver daughters' responses to the cancer diagnosis and its implications, the present analysis documents the scope of existential concerns and issues adult daughter caregivers may be experiencing. These findings suggest that treatment strategies that exclusively focus on the emotional responses to a family member's illness may inadvertently omit consideration of the broad array of salient issues and concerns that contribute to a family's plight. Consistent with a growing body of evidence in this area this investigation documents that caregiving daughters are vulnerable to a range of adverse reactions

As a function of their involvement in caregiving, they are exposed to various aspects of the disease and its treatment, giving them a first-hand knowledge of what it might be like to personally experience breast cancer. This potent combination of caring for a mother with breast cancer while worrying about one's own personal risk of developing the disease can engender

considerable distress. Indeed, as the daughters' narratives suggest, personal experiences with their mothers' illness may increase their sense of personal vulnerability and contribute to a diminished sense of future options.

Clinicians' appreciation of the existential plight that families may experience in this type of illness situation can be further informed by consideration of the family's specific developmental stage and the psychosocial concerns that are present at that stage. As the present investigation has discerned, with the aging family, a number of life-cycle developmental issues are present that impact the daughter's emotional response to their mother's diagnosis, alter the mother-daughter relationship and change the daughters' perception of personal risk. These issues include the role reversal that frequently occurs, with the adult daughter becoming the caregivers of their mother, possibly for the first time, as well as daughters' concerns over possible loss, fear of being orphaned, and worry over being next in line for the disease. Awareness that such issues are particularly germane when cancer strikes an older parent may help inform clinical encounters with family members.

An understanding of how daughters respond to their perception of increased risk and the value that they assign to screening and proactive health behaviors will also aid in the development of programs and materials to enhance adherence to recommended screening guidelines with this at risk population.

***So What?*** With the recent advances in genetics that have identified breast cancer genes (i.e., BCA1 and BCA2) it is now increasingly feasible for women to learn if they possess a genetic factor that places them at increased risk for breast cancer. As testing becomes more widely available, increasing numbers of daughters may be motivated to undergo genetic testing following their mother's diagnosis of breast cancer to assess their own risk. With the advances in genetic testing and clinical monitoring of at risk individuals, more health/mental health clinicians may be called up to deal with at risk women and may benefit from a more comprehensive understanding of the special psycho social issue manifested by at risk daughters. Mental health clinicians/ health care clinicians when called upon to provide counseling/respond to queries from this group, may be ill-equipped to respond to the unique psychosocial needs and concerns presented by these at risk women. Their special needs and concerns are generated by the circumstances that informed their risk status – having experienced the diagnosis of breast cancer in one or more of their first degree relatives. Little attention has been focused on what the meaning of the experience is to these daughters. Frequently adult daughters are called upon to provide not only emotional support but also practical assistance to their mothers during treatment. It was not well understood how this first-hand knowledge of the cancer experience may impact the daughter's fear of and dread/concerns associated with these dread disease and their sense of personal risk/own illness fears.

### List of Personnel on Grant

Monique Carrero  
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Maria Elena Ramos  
Victoria H. Raveis  
Pearl Rocca  
Tina Sapienza  
Karen Steinmayer  
Anthony Towle  
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Table 1. Sociodemographic Characteristics - Caregiving Daughters (n=59)

	<u>%</u>
<b>Age:</b>	
19 - 29	20
30 - 34	17
35 - 39	20
40 - 44	15
45 - 62	27
Mean (S.D.)	38.08 (9.90)
<b>Race:</b>	
White, Non-Hispanic	75
Black, Non-Hispanic	3
Hispanic	20
Other/Mixed	2
<b>Marital status:</b>	
Married	56
Never Married	34
Divorced/Separated/Widowed	10
<b>Number of children:</b>	
None	42
One	8
Two	32
Three or more	17
Mean (S.D.)	1.39 (1.59)
<b>Number in household (including respondent):</b>	
One	17
Two	22
Three	19
Four	24
Five or more	18
Mean (S.D.)	3.12 (1.56)
<b>Daughter lives...</b>	
With spouse/partner	59
With children	52
With patient	19

Table 1. Sociodemographic Characteristics - Caregiving Daughters (n=59) [continued]

	<u>%</u>
Education:	
≤ High school	10
Some college	20
College grad	37
Graduate/Professional degree	32
Work status:	
Not Employed	27
Employed (part-time)	17
Employed (full-time)	56

Table 2. Sociodemographic Characteristics - Patients (n=61)

	<u>%</u>
Age:	
47 - 60	18
60 - 69	46
70 - 79	30
80 - 86	7
Mean (S.D.)	66.23 (8.79)
Race:	
White, Non-Hispanic	74
Black, Non-Hispanic	3
Hispanic	21
Other/Mixed	2
Marital status:	
Married	54
Never Married	2
Divorced/Separated/Widowed	44
Education:	
≤ High school	38
Some college	21
College grad	18
Graduate/Professional degree	23
Work status:	
Not Employed	55
Employed (part-time)	25
Employed (full-time)	20
Number in household (including patient):	
One	26
Two	52
Three	8
Four	8
Five or more	5
Mean (S.D.)	2.13 (1.06)
Patient lives...	
With spouse/partner	56
With caregiving daughter	18
Alone	26

Table 3. Disease and Treatment Characteristics - Patients (n=61)

	<u>%</u>
Extent of cancer	
Local	69
Regional/Metastatic	31
Type of Treatment	
Surgery only	30
Surgery & Radiation	36
Surgery & Chemotherapy	13
Surgery/Radiation/Chemotherapy	21
Length of time since diagnosis	
≤ 6 months	28
6 - 12 months	67
> 1 year	5
Mean number of days (S.D.)	233.12 (84.18)

Table 4. Psychological Distress - Patients (n=55)

	<u>Mean (S.D.)</u>
Depressive Symptomatology	10.67 (9.70)
Percent at or above cutoff for probable caseness of depression:	18%
State Anxiety	34.84 (11.73)

Table 5. Patient Sociodemographics of Eligible Patient-Daughter Dyads by Study Participation (n=74)

	Participants (n=61)	Non-Participants (n=13)
	<u>%</u>	<u>%</u>
<b>Patient Age**:</b>		
45-59	18	7
60-69	48	31
70-79	30	23
80+	5	38
Mean age (S.D.)	65.74 (8.75)	72.15 (11.45)
<b>Patient Race:</b>		
White, Non-Hispanic	75	62
Black, Non-Hispanic	5	15
Hispanic	18	23
Other/Mixed	2	--
<b>Patient Marital status**:</b>		
Married	59	46
Never Married	--	15
Widowed/ Divorced/Separated	41	38
<b>Type of treatment:</b>		
Surgery	30	54
Surgery & Radiation	36	23
Surgery & Chemotherapy	13	8
Surgery/Radiation/Chemotherapy	21	8
No Treatment	--	8

\*\* -- p ≤ .01

Table 6. Comparison of Caregiving Daughter Sociodemographics by Patient's Extent of Disease

	Localized Cancer (n=41) %	Nonlocalized Cancer (n=18) %
Age:		
19 - 29	17	28
30 - 34	17	17
35 - 39	17	28
40 - 44	20	6
45 - 62	29	22
Mean Age (S.D.)	38.95 (9.40)	36.11 (10.97)
Race:		
White, Non-Hispanic	78	67
Black, Non-Hispanic	2	6
Hispanic	17	28
Other/Mixed	2	--
Education:		
≤ High school	10	11
Some college	22	17
College grad	32	50
Graduate/Professional degree	37	22
Work status:		
Not employed	24	33
Employed (part-time)	20	11
Employed (full-time)	56	5
Marital status:		
Never Married	29	44
Married	63	39
Widowed/Divorced/Separated	7	17
Has children:	61	50
Number of children		
None	39	50
One	10	6
Two	34	28
Three or more	17	17
Mean (S.D.)	1.39 (1.39)	1.39 (2.00)

Table 6. Comparison of Caregiving Daughter Sociodemographics by Patient's Extent of Disease [continued]

	Localized Cancer (n=41) <u>%</u>	Nonlocalized Cancer (n=18) <u>%</u>
Number in household, including respondent:		
One	15	22
Two	20	28
Three	20	17
Four	27	17
Five or more	18	17
Mean (S.D.)	3.27 (1.56)	2.83 (1.54)

Table 7. Perceived Risk of Breast Cancer - Caregiving Daughters (n≤57)

	<u>%</u>
Compared to other women your age, your chances of getting breast cancer are:	
Much lower	--
Somewhat lower	7
The same	21
Somewhat higher	49
Much higher	23
Perception of your own chances of developing breast cancer affected by mother's diagnosis:	
Had no effect on me	12
Made me feel somewhat more at risk	49
Made me feel a lot more at risk	39
Compared to other women <i>with</i> a relative with breast cancer, your chances of developing breast cancer are:	
Much lower	4
Somewhat lower	12
The same	57
Somewhat higher	21
Much higher	5
Compared to other women <i>without</i> a relative with breast cancer, your chances of developing breast cancer are:	
Much lower	2
Somewhat lower	4
The same	14
Somewhat higher	51
Much higher	30
Summary Perceived Risk:	
Low Risk	25
Moderate Risk	53
High Risk	23

Table 8. Extent of Cancer and Time Since Diagnosis (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14)	High Risk Group (n=11)
	<u>%</u>	<u>%</u>
Extent of Cancer:		
Local	64	64
Non-local	36	36
Time Since Diagnosis:		
Less than 6 months	29	18
6 - 12 months	64	82
More than one year	7	--

Table 9. Comparison of a 5 year Modified Gail Risk Assessment by Perceived Risk (n=25)

<b>Perceived Risk</b>	<u>Mean (S.D.)</u>	
Low	.99	(.90)
High	.76	(.85)

Table 10. Breast Cancer Screening History<sup>1</sup> (n≤25)

	<u>%</u>
Daughters 40 or older who conduct monthly breast self-examinations:	48
Daughters 40 or older who have regular mammograms:	92
Approximate # of months since last mammogram:	
1 - 3 months	13
4 - 6 months	39
7 - 9 months	4
10 - 12 months	35
12+	9
Mean number of months (S.D.)	9.46 (8.87)

<sup>1</sup> Restricted to daughters 40 or older.

Table 11. Impact of Event/Fear of Cancer - Caregiving Daughters (n≤57)

	<u>Mean (S.D.)</u>
Impact of Event/Fear of Cancer Scale - Global	15.52 (10.63)
Intrusion Subscale:	8.96 ( 6.73)
Avoidance Subscale:	6.56 ( 5.94)

Table 12. Caregiving Daughters' Scores on Impact of Event Scale (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14)	High Risk Group (n=10)
	<u>Mean</u> <u>(S.D.)</u>	<u>Mean</u> <u>(S.D.)</u>
Impact of Event/Fear of Cancer Scale	13.28 (11.40)	13.90 (10.69)
Intrusion Subscale:	7.28 ( 6.39)	8.60 ( 6.80)
Avoidance Subscale:	6.00 ( 6.68)	5.63 ( 5.02)

Table 13. Change in Mother-Daughter Relationship – Mother and Caregiving Daughter Perspective (n≤53)

	Daughter Perspective		Patient Perspective			
	Mean	(S.D.)	%	Mean	(S.D.)	%
<b>Conflict Subscale:</b>						
Conflict since mother's illness	1.62 <sub>a</sub>	( .49)		1.49 <sub>b</sub>	( .50)	
Conflict prior to mother's illness	1.85 <sub>a</sub>	( .66)		1.60 <sub>b</sub>	( .51)	
Get upset or mad at each other:						
Worse			6			2
Same			69			81
Better			25			17
How much they disagree and quarrel:						
Worse			8			8
Same			71			71
Better			21			21
How much they argue:						
Worse			6			6
Same			75			81
Better			19			13
<b>Satisfaction Subscale:</b>						
Satisfaction since mother's illness	3.78 <sub>c</sub>	(1.06)		4.22 <sub>d</sub>	( .90)	
Satisfaction prior to mother's illness	3.58 <sub>c</sub>	(1.06)		4.10 <sub>d</sub>	( .88)	
Satisfied with relationship:						
Worse			6			4
Same			75			81
Better			19			15
Happy with the way things are between them:						
Worse			8			4
Same			81			77
Better			12			19
How good the relationship is:						
Worse			4			--
Same			69			79
Better			27			21

**Note:** Means sharing a subscript differ significantly from each other (p≤.043) based on results of paired t-test.

Table 13. Change in Mother-Daughter Relationship – Mother and Caregiving Daughter Perspective (n≤53) [continued]

	Daughter Perspective		Patient Perspective			
	Mean	(S.D.)	%	Mean	(S.D.)	%
<b>Intimacy Subscale:</b>						
Intimacy since mother's illness	2.97	(1.13)		3.86 <sub>e</sub>	(1.06)	
Intimacy prior to mother's illness	3.10	(1.18)		3.45 <sub>e</sub>	(1.13)	
How much they tell each other everything:						
Worse			17			6
Same			79			62
Better			4			32
Share secrets and private feelings with each other:						
Worse			19			2
Same			71			74
Better			10			24
Talk about things they don't want other people to know:						
Worse			17			4
Same			73			77
Better			10			19
<b>Nurturance Subscale:</b>						
Nurturance since mother's illness	3.72 <sub>f</sub>	(.86)		3.10	(1.04)	
Nurturance prior to mother's illness	2.79 <sub>f</sub>	(1.02)		3.22	(1.07)	
Help with things they can't do themselves:						
Worse			--			24
Same			17			70
Better			83			6
Protect and look out for each other:						
Worse			--			4
Same			46			94
Better			54			2
Take care of other person:						
Worse			--			11
Same			23			83
Better			77			6

**Note:** Means sharing a subscript differ significantly from each other (p≤.043) based on results of paired t-test.

Table 13. Change in Mother-Daughter Relationship – Mother and Caregiving Daughter Perspective (n≤53) [continued]

	Daughter Perspective		Patient Perspective			
	Mean	(S.D.)	%	Mean	(S.D.)	%
<b>Admiration Subscale:</b>						
Admiration since mother's illness	3.90 <sub>g</sub>	( .96)		4.00	( .94)	
Admiration prior to mother's illness	3.74 <sub>g</sub>	( .98)		3.95	( .90)	
Treated like they are admired and respected:						
Worse			2			2
Same			73			85
Better			25			13
Treated like they are good at many things:						
Worse			6			6
Same			75			89
Better			19			6
Felt that things they do are liked or approved:						
Worse			4			6
Same			85			87
Better			12			8
<b>Relative Power Subscale:</b>						
Relative power since mother's illness	3.16 <sub>h</sub>	(1.04)		3.05 <sub>i</sub>	( .75)	
Relative power prior to mother's illness	2.73 <sub>h</sub>	(1.00)		3.30 <sub>i</sub>	( .74)	
Tells the other person what to do more often:						
Parent more			2			23
Same			56			77
Daughter more			42			--
Who tends to be the boss:						
Parent more			2			15
Same			67			85
Daughter more			31			--
Who tends to take charge and decide what's done:						
Parent more			2			11
Same			67			87
Daughter more			31			2

**Note:** Means sharing a subscript differ significantly from each other (p≤.043) based on results of paired t-test.

Table 14. Caregiving Daughters' Report of a Change in Mother-Daughter Relationship  
(Restricted to Low and High Perceived Risk Groups)

	Low Risk (n=14)	High Risk (n=11)		
	<u>Mean</u> (S.D.)	<u>%</u>	<u>Mean</u> (S.D.)	<u>%</u>
<b>Conflict Subscale:</b>				
Conflict since mother's illness	1.48 (.53)		1.85 (.38)	
Conflict prior to mother's illness *	1.55 (.66)		2.06 (.49)	
Get upset or mad at each other:				
Worse	7		--	
Same	71		81	
Better	21		17	
How much they disagree and quarrel:				
Worse	7		--	
Same	86		82	
Better	7		18	
How much they argue:				
Worse	7		--	
Same	79		82	
Better	14		18	
<b>Satisfaction Subscale:</b>				
Satisfaction since mother's illness	3.76 (1.14)		3.79 (.91)	
Satisfaction prior to mother's illness	3.66 (1.20)		3.73 (.83)	
Satisfied with relationship:				
Worse	--		--	
Same	86		100	
Better	14		--	
Happy with the way things are between them:				
Worse	--		9	
Same	100		82	
Better	--		9	
How good the relationship is:				
Worse	--		--	
Same	86		82	
Better	14		18	

\* -- p ≤ .05

Table 14. Caregiving Daughters' Report of a Change in Mother-Daughter Relationship  
 (Restricted to Low and High Perceived Risk Groups) [continued]

	Low Risk (n=14)			High Risk (n=11)		
	<u>Mean</u>	<u>(S.D.)</u>	<u>%</u>	<u>Mean</u>	<u>(S.D.)</u>	<u>%</u>
<b>Intimacy Subscale:</b>						
Intimacy since mother's illness	3.07	(1.39)		3.21	(.86)	
Intimacy prior to mother's illness	3.17	(1.37)		3.51	(.97)	
How much they tell each other everything:						
Worse			14			36
Same			86			64
Better			--			--
Share secrets and private feelings with each other:						
Worse			7			36
Same			86			46
Better			7			18
Talk about things they don't want other people to know:						
Worse			14			27
Same			86			64
Better			--			9
<b>Nurturance Subscale:</b>						
Nurturance since mother's illness	3.43	(1.06)		3.94	(.61)	
Nurturance prior to mother's illness	2.76	(1.13)		2.94	(.66)	
Help with things they can't do themselves:						
Worse			--			--
Same			29			9
Better			71			91
Protect and look out for each other:						
Worse			--			--
Same			57			36
Better			43			64
Take care of other person:						
Worse			--			--
Same			29			18
Better			71			82

Table 14. Caregiving Daughters' Report of a Change in Mother-Daughter Relationship  
(Restricted to Low and High Perceived Risk Groups) [continued]

	Low Risk (n=14)			High Risk (n=11)		
	<u>Mean</u>	<u>(S.D.)</u>	<u>%</u>	<u>Mean</u>	<u>(S.D.)</u>	<u>%</u>
<b>Admiration Subscale:</b>						
Admiration since mother's illness	3.90	( .88)		3.85	(1.00)	
Admiration prior to mother's illness	3.76	(1.02)		3.73	(1.03)	
Treated like they are admired and respected:						
Worse			--			--
Same			86			82
Better			14			18
Treated like they are good at many things:						
Worse			--			--
Same			79			82
Better			21			18
Felt that things they do are liked or approved:						
Worse			--			--
Same			93			100
Better			7			--
<b>Relative Power Subscale:</b>						
Relative power since mother's illness	3.31	( .96)		2.91	(1.19)	
Relative power prior to mother's illness	2.88	( .81)		2.52	(1.02)	
Tells the other person what to do more often:						
Parent more			--			--
Same			57			73
Daughter more			43			27
Who tends to be the boss:						
Parent more			--			--
Same			79			64
Daughter more			21			36
Who tends to take charge and decide what's done:						
Parent more			--			--
Same			71			82
Daughter more			29			18

Table 15. Sense of Filial Obligation - Caregiving Daughters (n=58)

	<u>%</u>
Married children should live close to parents to provide care:	
Strongly agree	34
Somewhat agree	33
Neither agree nor disagree	5
Somewhat disagree	21
Strongly disagree	7
Children should not be expected to do tasks for their parents:	
Strongly agree	75
Somewhat agree	16
Neither agree nor disagree	--
Somewhat disagree	3
Strongly disagree	5
Parents should expect adult children to assist them:	
Strongly agree	52
Somewhat agree	33
Neither agree nor disagree	3
Somewhat disagree	9
Strongly disagree	3
It is a child's duty to assist parents:	
Strongly agree	48
Somewhat agree	38
Neither agree nor disagree	2
Somewhat disagree	10
Strongly disagree	2
It is preferable to pay a professional for assistance with caregiving:	
Strongly agree	19
Somewhat agree	43
Neither agree nor disagree	14
Somewhat disagree	24
Strongly disagree	--

Table 15. Sense of Filial Obligation - Caregiving Daughters (n=58) [continued]

	<u>%</u>
Paying for professional help means a relative is not taking responsibility:	
Strongly agree	10
Somewhat agree	12
Neither agree nor disagree	2
Somewhat disagree	40
Strongly disagree	36
It is better to give up a job to provide care than to pay a professional:	
Strongly agree	7
Somewhat agree	10
Neither agree nor disagree	12
Somewhat disagree	29
Strongly disagree	41

Table 16. Sense of Filial Obligation: Global and Subscale Scores - Caregiving Daughters  
(n=58)

	<u>Mean</u> <u>(S.D.)</u>
Filial Obligation Scale - Global	24.52 (3.61)
Attitudes regarding filial responsibilities:	12.95 (2.44)
Attitudes regarding use of paid help:	5.78 (1.92)

Table 17. Sense of Filial Obligation - Patients (n=55)

	<u>%</u>
Married children should live close to parents to provide care:	
Strongly agree	16
Somewhat agree	18
Neither agree nor disagree	--
Somewhat disagree	33
Strongly disagree	33
Children should not be expected to do tasks for their parents:	
Strongly agree	31
Somewhat agree	34
Neither agree nor disagree	2
Somewhat disagree	16
Strongly disagree	16
Parents should expect adult children to assist them:	
Strongly agree	20
Somewhat agree	33
Neither agree nor disagree	4
Somewhat disagree	26
Strongly disagree	18
It is a child's duty to assist parents:	
Strongly agree	24
Somewhat agree	29
Neither agree nor disagree	--
Somewhat disagree	22
Strongly disagree	26
It is preferable to pay a professional for assistance with caregiving:	
Strongly agree	14
Somewhat agree	29
Neither agree nor disagree	9
Somewhat disagree	16
Strongly disagree	31

Table 17. Sense of Filial Obligation - Patients (n=55) [continued]

	<u>%</u>
Paying for professional help means a relative is not taking responsibility:	
Strongly agree	6
Somewhat agree	11
Neither agree nor disagree	7
Somewhat disagree	33
Strongly disagree	44
It is better to give up a job to provide care than to pay a professional:	
Strongly agree	4
Somewhat agree	6
Neither agree nor disagree	4
Somewhat disagree	27
Strongly disagree	60

Table 18. Sense of Filial Obligation: Global and Subscale Scores - Patients (n=55)

	<u>Mean (S.D.)</u>
Filial Obligation Scale - Global	18.62 (5.17)
Attitudes regarding filial responsibilities:	9.62 (3.36)
Attitudes regarding use of paid help:	4.82 (1.81)

Table 19. Caregiving Daughters' Sense of Filial Obligation by Perceived Risk of Breast Cancer  
(Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Married children should live close To parent to provide care:		
Strongly Disagree	14	--
Somewhat Disagree	29	18
Neither Agree nor Disagree	7	--
Somewhat Agree	21	27
Strongly Agree	29	54
Children should not be expected to do tasks for their parents:		
Strongly agree	14	--
Somewhat agree	--	--
Neither agree nor disagree	--	--
Somewhat disagree	29	18
Strongly disagree	57	82
Parents should expect adult children to assist them:		
Strongly agree	57	64
Somewhat agree	21	27
Neither agree nor disagree	7	--
Somewhat disagree	7	9
Strongly disagree	7	--
It is a child's duty to assist parents:		
Strongly agree	36	46
Somewhat agree	50	36
Neither agree nor disagree	2	--
Somewhat disagree	7	18
Strongly disagree	7	--
It is preferable to pay a professional for assistance with caregiving: *		
Strongly agree	--	--
Somewhat agree	14	46
Neither agree nor disagree	21	9
Somewhat disagree	57	9
Strongly disagree	7	36

\* -- p ≤ .05

Table 19. Caregiving Daughters' Sense of Filial Obligation by Perceived Risk of Breast Cancer  
 (Restricted to Low and High Perceived Risk Groups) [continued]

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Paying for professional help means a relative is not taking responsibility:		
Strongly agree	7	--
Somewhat agree	7	9
Neither agree nor disagree	--	9
Somewhat disagree	29	54
Strongly disagree	57	27
It is better to give up a job to provide care than to pay a professional:		
Strongly agree	7	9
Somewhat agree	10	9
Neither agree nor disagree	14	--
Somewhat disagree	21	36
Strongly disagree	57	46
	<u>Mean</u> (S.D.)	<u>Mean</u> (S.D.)
Filial Obligation Scale	22.57 (3.23)	24.90 (3.80)
Attitudes regarding filial responsibilities:	12.29 (3.17)	13.36 (2.11)
Attitudes regarding use of paid help:	5.36 (1.78)	5.36 (1.43)

Table 20. Number of Activity Tasks and Activity Domains Caregiving Daughter Provided to Patient (n≤58).

	<u>%</u>
<b>Number of Activity Tasks Provided Help</b>	
1 - 5	29
6 - 10	48
11 - 15	22
Mean (S.D.)	7.66 (3.6)
<b>Number of Activity Domains Provided Help</b>	
One	3
Two	14
Three	21
Four	19
Five	36
Mean (S.D.)	3.93 (1.35)

Table 21. Activity Domains Where Caregiving Daughter Provided Help (n≤58)

<b>Activity Domains</b>	<u>%</u>
Home Health Activities: (Medication, Changing dressing)	47
Instrumental Activities: (Meals, Housework, Shopping)	93
Personal Activities: (Bathing, Dressing, Mobility)	60
Transportation Activities: (Treatment, Shopping, Visits, Work)	93
Administrative Activities: (Filling-Out Forms, Banking, Information)	91
Legal Activities: (Illness-related legal counseling)	2
Formal Health Care Activities: (Obtaining and coordinating formal health care)	7

Table 22. Number of Activity Tasks and Activity Domains Caregiving Daughter Provided to Patient (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
<b>Number of Activity Tasks Provided Help*</b>		
1 - 5	43	27
6 - 10	57	27
11 - 15	--	46
Mean (S.D.) **	5.7 (2.7)	9.0 (3.2)
<b>Number of Activity Domains Provided Help</b>		
Two	29	9
Three	29	9
Four	29	18
Five	14	64
Mean (S.D.)	3.29 (1.07)	4.36 (1.03)

\*\* -- p ≤ .01; \* -- p ≤ .05

Table 23. Activity Domains Where Caregiving Daughter Provided Help (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
<b>Activity Domains</b>		
Home Health Activities: ** (Medication, Changing dressing)	14	64
Instrumental Activities: (Meals, Housework, Shopping)	86	100
Personal Activities: (Bathing, Dressing, Mobility)	50	82
Transportation Activities: (Treatment, Shopping, Visits, Work)	93	100
Administrative Activities: (Filling-Out Forms, Banking, Information)	86	91

\*\* --  $p \leq .01$

Table 24. Social Burden - Caregiving Daughters (n≤58)

	<u>%</u>
Extent that illness has reduced the amount of time daughter spends with friends, neighbors, and acquaintances:	
A great deal	10
Somewhat	12
Only a little	34
Not at all	43
Extent that illness has reduced daughter's outside activities such as hobbies and vacations:	
A great deal	12
Somewhat	9
Only a little	26
Not at all	53
Extent that illness has reduced daughter's time to take care of household duties and tasks:	
Often	16
Sometimes	24
Rarely	29
Never	31
Extent that illness has made it difficult to establish a daily routine and plan activities:	
Not at all	46
Only a little	30
Somewhat	16
A great deal	9
Extent that illness has reduced daughter's time with other family members:	
A great deal	2
Somewhat	14
Only a little	28
Not at all	57

Table 25. Time Burden - Caregiving Daughters (n=58)

	<u>%</u>
Has cut down on time spent doing regular daily activities due to her caregiving:	60
Feels that she has accomplished less than she would like due to her caregiving:	34
Doesn't do regular activities as carefully as usual:	34

Table 26. Physical Burden - Caregiving Daughters (n=58)

	<u>%</u>
Amount of physical strain daughter experienced from caregiving since the diagnosis:	
A great deal of strain	9
A moderate amount of strain	29
A little strain	22
No strain	40
Extent caregiving has affected daughter's energy for her regular daily activities:	
A lot less energy	9
Somewhat less energy	3
A little less energy	38
No change in energy	50

Table 27. Financial Burden - Caregiving Daughters (n=58)

	<u>%</u>
Seriousness of daughter's financial problems due to patient's illness:	
Very serious	2
Somewhat serious	3
Not very serious	3
No financial problems	91
Extent of financial changes in daughter's habits and lifestyle due to her caregiving:	
Many changes	7
Some changes	--
A few changes	15
No changes at all	78
Extent that illness has caused daughter to pass up financial opportunities:	
To a great extent	2
To some extent	5
To a small extent	12
Not at all	81

Table 28. Employment Burden<sup>1</sup> - Caregiving Daughters (n≤57)

%

Extent to which caregiving affected daughter's ability to concentrate on the job or to do her best at work:

Does not apply	--
To a great extent	12
To some extent	34
To a small extent	37
Not at all	17

Since diagnosis, daughter has come in late or left early because patient was sick, had to be taken to a medical appointment, or needed errands run:

NUMBER OF TIMES:

None	45
1 or 2	24
3 - 4	10
5 + times	21

Mean (S.D.)      3.00 (5.57)

Number of times since diagnosis daughter has taken days off from work as "sick", vacation, or personal days because the patient felt sick, had to be taken to a medical appointment, or needed errands run:

NUMBER OF TIMES:

None	29
1 or 2	17
3 - 4	17
5+ times	38

Mean (S.D.)      3.67 (3.64)

<sup>1</sup> Restricted to those reporting this occurrence.

Table 29. Caregiving Daughters' Social Burden (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Extent that illness has reduced the amount of time daughter spends with friends, neighbors, and acquaintances:		
A great deal	--	--
Somewhat	7	36
Only a little	36	18
Not at all	57	46
Extent that illness has reduced daughter's outside activities such as hobbies and vacations:		
A great deal	--	18
Somewhat	--	--
Only a little	36	27
Not at all	64	54
Extent that illness has reduced daughter's time to take care of household duties and tasks:		
Often	14	18
Sometimes	7	27
Rarely	29	36
Never	50	18
Extent that illness has made it difficult to establish a daily routine and plan activities:		
Not at all	71	27
Only a little	21	46
Somewhat	--	18
A great deal	7	9
Extent that illness has reduced daughter's time with other family members: *		
A great deal	--	--
Somewhat	--	36
Only a little	29	27
Not at all	71	36

\* -- p ≤ .05

Table 30. Caregiving Daughters' Time Burden (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Has cut down on time spend doing regular Daily activities due to her caregiving:	36	73
Feels that she has accomplished less than she would like due to her caregiving:	21	36
Doesn't do regular activities as carefully as usual:	29	54

Table 31. Caregiving Daughters' Physical Burden (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Amount of physical strain daughter experienced from caregiving since the diagnosis: **		
A great deal of strain	--	18
A moderate amount of strain	7	54
A little strain	29	9
No strain	64	18
Extent caregiving has affected daughter's energy for her regular daily activities:		
A lot less energy	7	9
Somewhat less energy	--	--
A little less energy	43	36
No change in energy	50	54

\*\* -- p ≤ .01

Table 32. Caregiving Daughters' Financial Burden (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Seriousness of daughter's financial problems due to patient's illness:		
Very serious	--	--
Somewhat serious	--	--
Not very serious	--	--
No financial problems	100	100
Extent of financial changes in daughter's habits and lifestyle due to her caregiving:		
Many changes	--	9
Some changes	--	--
A few changes	7	18
No changes at all	93	73
Extent that illness has caused daughter to pass up financial opportunities		
To a great extent	--	9
To some extent	7	--
To a small extent	--	18
Not at all	93	73

Table 33. Caregiving Daughters' Employment Burden<sup>1</sup> (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=11) <u>%</u>	High Risk Group (n=8) <u>%</u>
Extent to which caregiving affected daughter's ability to concentrate on the job or to do her best at work:		
Does not apply	21	27
To a great extent	7	18
To some extent	21	18
To a small extent	29	27
Not at all	21	9
Since diagnosis, daughter has come in late or left early because patient was sick, had to be taken to a medical appointment, or needed errands run:		
NUMBER OF TIMES:		
None	36	50
1 or 2	46	38
3 – 4	9	12
5 + times	9	--
Mean (S.D.)	1.91 (.94)	1.62 (.74)
Number of times since diagnosis daughter has taken days off from work as "sick", vacation, or personal days because the patient felt sick, had to be taken to a medical appointment, or needed errands run:		
NUMBER OF TIMES:		
None	46	12
1 or 2	27	12
3 – 4	18	25
5+ times	9	50
Mean (S.D.)*	1.91 (1.04)	3.12 (1.13)

\* p ≤ .05

<sup>1</sup> Restricted to those reporting this occurrence.

Table 34. Appraisal of Illness Predictability - Caregiving Daughters (n=58)

	<u>%</u>
Know when mother is going to have good or bad day:	
Strongly agree	12
Somewhat agree	9
Neither Agree nor disagree	7
Somewhat disagree	26
Strongly disagree	47
Clear when mother's illness is getting better or worse:	
Strongly agree	9
Somewhat agree	14
Neither Agree nor disagree	9
Somewhat disagree	16
Strongly disagree	53
Can generally predict the course of mother's illness:	
Strongly agree	28
Somewhat agree	21
Neither Agree nor disagree	21
Somewhat disagree	17
Strongly disagree	14
Mother's physical distress is predictable:	
Strongly agree	9
Somewhat agree	12
Neither Agree nor disagree	10
Somewhat disagree	34
Strongly disagree	34
Summary Scale:	
Mean (S.D.)	14.21 (3.85)

Table 35. Appraisal of Illness Predictability - Patients (n≤60)

	<u>%</u>
I usually know when I'm going to have a good or bad day:	
Strongly agree	33
Somewhat agree	17
Neither Agree nor disagree	10
Somewhat disagree	23
Strongly disagree	17
It's clear to me when my illness is getting better or worse:	
Strongly agree	41
Somewhat agree	25
Neither Agree nor disagree	19
Somewhat disagree	7
Strongly disagree	8
I can generally predict the course of my illness:	
Strongly agree	12
Somewhat agree	15
Neither Agree nor disagree	20
Somewhat disagree	27
Strongly disagree	27
My physical distress is predictable:	
Strongly agree	32
Somewhat agree	22
Neither Agree nor disagree	20
Somewhat disagree	17
Strongly disagree	10
Summary Scale:	
Mean (S.D.)	13.09 (3.44)

Table 36. Caregiving Daughters' Appraisal of Illness Predictability (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Know when mother is going to have good or bad day:		
Strongly agree	29	--
Somewhat agree	14	--
Neither agree nor disagree	7	9
Somewhat disagree	29	27
Strongly disagree	21	64
Clear when mother's illness is getting better or worse:		
Strongly agree	7	--
Somewhat agree	14	18
Neither agree nor disagree	7	--
Somewhat disagree	36	9
Strongly disagree	36	73
Can generally predict the course of mother's illness:		
Strongly agree	36	9
Somewhat agree	14	46
Neither agree nor disagree	21	18
Somewhat disagree	21	--
Strongly disagree	7	27
Mother's physical distress is predictable:		
Strongly agree	14	--
Somewhat agree	14	9
Neither Agree nor disagree	7	9
Somewhat disagree	43	27
Strongly disagree	21	54
Summary Scale: **		
Mean (S.D.)	12.71 (3.54)	16.09 (1.87)

\*\* -- p ≤ .01

Table 37. Appraisal of Personal Control Over Illness - Caregiving Daughters (n=58)

	<u>%</u>
Personal control over amount of fatigue mother experiences from day to day:	
No control	26
Very little control	33
A moderate amount of control	26
Quite a bit of control	12
An extreme amount of control	3
Personal control over amount of discomfort mother experiences from day to day:	
No control	22
Very little control	40
A moderate amount of control	26
Quite a bit of control	9
An extreme amount of control	2
Does not apply	2
Personal control over amount of immobility mother experiences from day to day:	
No control	2
Very little control	2
A moderate amount of control	2
Quite a bit of control	2
Does not apply	93
Personal control over amount of pain mother experiences from day to day:	
No control	36
Very little control	29
A moderate amount of control	21
Quite a bit of control	5
Does not apply	9
Personal control over long-term course of mother's illness:	
No control	43
Very little control	28
A moderate amount of control	19
Quite a bit of control	9
An extreme amount of control	2

Table 37. Appraisal of Personal Control Over Illness - Caregiving Daughters (n=58)[continued]

	<u>%</u>
Personal control over the medical care and treatment of mother's illness:	
No control	10
Very little control	14
A moderate amount of control	29
Quite a bit of control	41
An extreme amount of control	5
Summary Scale:	
Mean (S.D.)	3.65 (.75)

Table 38. Appraisal of Personal Control Over Illness - Patients (n=60)

	<u>%</u>
Personal control over amount of fatigue patient experiences from day to day:	
No control	8
Very little control	18
A moderate amount of control	35
Quite a bit of control	28
An extreme amount of control	8
Does not apply	2
Personal control over amount of discomfort patient experiences from day to day:	
No control	8
Very little control	25
A moderate amount of control	22
Quite a bit of control	37
An extreme amount of control	5
Does not apply	3
Personal control over amount of immobility patient experiences from day to day:	
No control	3
Very little control	2
A moderate amount of control	--
Quite a bit of control	--
Does not apply	95
Personal control over amount of pain patient experiences from day to day:	
No control	3
Very little control	8
A moderate amount of control	27
Quite a bit of control	20
An extreme amount of control	8
Does not apply	33
Personal control over long-term course of patient's own illness:	
No control	27
Very little control	7
A moderate amount of control	28
Quite a bit of control	28
An extreme amount of control	10

Table 38. Appraisal of Personal Control Over Illness - Patients (n=60) [continued]

	<u>%</u>
Personal control over the medical care and treatment of patient's own illness:	
No control	3
Very little control	10
A moderate amount of control	18
Quite a bit of control	43
An extreme amount of control	25
Summary Scale:	
Mean (S.D.)	2.20 (.72)

Table 39. Caregiving Daughters' Appraisal of Personal Control Over Illness (Restricted to Low and High Perceived Risk Groups)

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Personal control over amount of fatigue mother experiences from day to day:		
No control	43	9
Very little control	29	46
A moderate amount of control	21	36
Quite a bit of control	7	9
An extreme amount of control	--	--
Personal control over amount of discomfort mother experiences from day to day:		
No control	36	9
Very little control	36	64
A moderate amount of control	21	27
Quite a bit of control	7	--
Personal control over amount of immobility mother experiences from day to day:		
No control	--	--
Very little control	--	--
A moderate amount of control	--	9
Quite a bit of control	--	--
Does not apply	100	91
Personal control over amount of pain mother experiences from day to day:		
No control	50	18
Very little control	14	46
A moderate amount of control	21	27
Quite a bit of control	--	--
Does not apply	14	9
Personal control over long-term course of mother's illness:		
No control	50	36
Very little control	36	27
A moderate amount of control	14	36
Quite a bit of control	--	--
An extreme amount of control	--	--

Table 39. Caregiving Daughters' Appraisal of Personal Control Over Illness (Restricted to Low and High Perceived Risk Groups) [continued]

	Low Risk Group (n=14) <u>%</u>	High Risk Group (n=11) <u>%</u>
Personal control over the medical care and treatment of mother's illness:		
No control	14	9
Very little control	7	9
A moderate amount of control	36	46
Quite a bit of control	43	27
An extreme amount of control	--	9
Summary Scale:		
Mean (S.D.)	3.94 (.66)	3.59 (.43)

Table 40. Psychological Distress - Caregiving Daughters (n=58)

	<u>Mean (S.D.)</u>
Depressive Symptomatology	8.29 (7.63)
Percent at or above cutoff for Probable caseness of depression:	12%
State Anxiety	34.72 (12.18)

Table 41. Caregiving Daughters' Psychological Distress by Perceived Risk of Breast Cancer  
 (Restricted to Low and High Perceived Risk Groups)

	<u>Low Risk Group</u> (n=14)	<u>High Risk Group</u> (n=11)
	<u>Mean (S.D.)</u>	<u>Mean (S.D.)</u>
Depressive Symptomatology	7.00 ( 6.10)	8.45 (6.04)
Percent at or above cutoff for probable caseness of depression:	7%	9%
State-Trait Anxiety	32.57 (11.22)	29.54 (9.61)

Table 42. Correlates of Depression and Anxiety for Caregiving Daughters by Potential Risk Factors (n≤58)

	Depression	Anxiety
<b>Patient/Disease Characteristics</b>		
Extent of Cancer	.324 **	.253 *
Length of Time Since Diagnosis	.092	.091
Cancer Treatments Received <sup>1</sup>		
Chemotherapy	.125	.215
Radiation	-.138	-.132
Chemotherapy & Radiation	-.231 *	-.084
<b>Daughter Sociodemographics</b>		
Age	-.096	-.132
White	-.186	.034
Married	-.261 *	-.248 *
Education	-.312 **	-.056
Employment Status	-.123	.020
Number of Children	-.172	-.218 *
Number in Household	-.209	-.201
Daughter Lives w/		
Spouse	-.155	-.159
Child	-.073	-.179
Mother	.121	.143
<b>Daughter's Relationship with Her Mother</b>		
Filial Responsibility – Total Score	.060	.044
Personal Responsibility Subscale	-.031	-.026
Attitudes Re: Use of Paid Help Subscale	.028	.060
Relationship w/Mother (NRI) – Prior to Mother's Illness:		
Conflict	.310 **	.437 ***
Satisfaction	-.276 *	-.353 **
Intimacy	-.059	-.072
Nurturance	.010	-.120
Admiration	-.280 *	-.280 *
Relative Power	-.191	-.021
Relationship w/Mother (NRI) – Since Mother's Illness		
Conflict	.191	.131
Satisfaction	-.313 **	-.269 *
Intimacy	-.097	-.058
Nurturance	.135	.048
Admiration	-.307 **	-.190
Relative Power	-.150	.106

<sup>1</sup> All patients also received surgery.

Table 42. Correlates of Depression and Anxiety for Caregiving Daughters by Potential Risk Factors (n≤58) [continued]

	Depression	Anxiety
<b>Daughter's C caregiving Burden</b>		
# Tasks Provided (range 0-18)	.059	-.052
# Domains of Tasks Provided (range 0-8)	.084	-.025
Provided Assistance with:		
Personal Activities	.036	-.059
Instrumental Activities	.056	.061
Home Health Activities	.019	-.116
Transportation Activities	-.115	-.130
Administrative Activities	.109	.110
Legal Activities	.444 ***	.359 **
Arranging Formal Health Care	.052	-.011
<b>Daughter's Appraisal of Mother's Illness</b>		
Illness Predictability	-.270 *	-.188
Illness Control	.090	.054
<b>Daughter's Cancer Risk</b>		
Perceived	-.041	.054
5-yr Risk (Modified Gail)	-.124	-.108
<b>Daughter's Appraisal of Impact Mother's Illness Has Had on Her</b>		
Impact of Event – Total Score	.454 ***	.463 ***
Intrusion Subscale	.306 *	.381 **
Avoidance Subscale	.421 ***	.356 **
<b>Daughter's Psychological Well-Being</b>		
Depression (CES-D) – Total Score	N/A	.671 ***
Depressive Affect Subscale	N/A	.614 ***
Positive Affect Subscale	N/A	-.415 ***
Somatic Vegetative Subscale	N/A	.583 ***
Interpersonal Distress Subscale	N/A	.305 *
Anxiety (STAIY-S)	.671 ***	N/A

\* p ≤ .05; \*\* p ≤ .01; \*\*\* p ≤ .001

Table 43. Depression and Anxiety - Caregiving Daughters by Types of Burden (n≤58).

	Depression Mean (S.D.)	Sig.	State Anxiety Mean (S.D.)	Sig.
<b>Social Burden</b>				
Extent that illness has reduced daughter's time to take care of household duties and tasks:				
Never	8.28 ( 6.77)		35.78 (12.41)	
Rarely	7.70 ( 6.59)		32.65 (12.02)	
Sometimes	8.71 ( 8.42)		35.86 (13.83)	
Often	8.78 (10.70)		34.78 (10.78)	
Extent that illness has made it difficult to establish a daily routine and plan activities:				
Not at all	7.92 ( 6.12)		33.19 (11.66)	
Only a little	8.06 ( 9.08)		33.35 (12.11)	
Somewhat	8.00 ( 6.63)		38.56 (12.91)	
A great deal	6.60 ( 4.62)		34.40 ( 7.76)	
Extent that illness has reduced daughter's time with other family members:				
Not at all	7.60 ( 6.20)		34.06 (11.66)	
Only a little	8.69 ( 8.50)		34.62 (11.75)	
Somewhat	11.25 (11.13)		37.62 (16.72)	
A great deal	1.00 (--)		35.00 (--)	
Extent that illness has reduced the amount of time daughter spends with friends, neighbors, and acquaintances:				
Not at all	7.84 ( 6.57)		32.24 (10.28)	
Only a little	8.85 ( 8.04)		36.15 (13.13)	
Somewhat	6.57 ( 6.83)		29.57 ( 9.81)	
A great deal	10.33 (11.99)		46.33 (13.26)	
Extent that illness has reduced daughter's outside activities such as hobbies and vacations:				
Not at all	7.55 ( 5.89)		30.71 (10.57)	
Only a little	8.67 ( 9.61)		38.13 (11.84)	
Somewhat	7.80 ( 7.56)		41.60 (12.18)	
A great deal	11.14 (10.65)		40.28 (15.42)	
<b>Time Burden</b>				
Has cut down on time spent doing regular daily activities due to caregiving:				
Yes	8.23 ( 8.38)		36.48 (12.96)	
No	8.39 ( 6.50)		32.04 (10.61)	

Table 43. Depression and Anxiety - Caregiving Daughters by Types of Burden (n≤58)  
 [continued]

	Depression Mean (S.D.)	Sig.	State Anxiety Mean (S.D.)	Sig.
Feels that she has accomplished less than she would like due to her caregiving:				
Yes	8.40 (10.31)		36.05 (13.88)	
No	8.24 ( 5.93)		34.02 (11.33)	
Doesn't do regular activities as carefully as usual:				
Yes	8.20 (10.00)		30.75 (12.26)	
No	8.34 ( 6.19)		36.82 (11.76)	
<b>Physical Burden</b>				
Amount of physical strain daughter experienced from caregiving since the diagnosis:				
No strain	7.78 ( 5.64)		33.22 (11.50)	
A little strain	10.31 ( 6.84)		39.31 (13.08)	
A moderate amount	6.24 ( 8.76)		31.59 (10.19)	
A great deal of strain	12.40 (12.42)		40.40 (17.18)	
Extent caregiving has affected daughter's energy for her regular daily activities:				
A lot less energy	12.40 (11.70)		36.20 (16.42)	
Somewhat less energy	7.00 ( 8.48)		41.00 ( 8.48)	
A little less energy	8.14 ( 8.33)		34.50 (11.44)	
As much energy	7.79 ( 6.40)		34.21 (12.62)	
<b>Employment Burden</b>				
Since diagnosis, daughter has come in late or left early because patient was sick, had to be taken to a medical appointment, or needed errands run:				
None	7.58 ( 6.99)		34.74 (12.87)	
1-2	8.30 ( 3.94)		34.60 ( 9.97)	
3-4	13.00 (15.03)		44.25 (15.48)	
5+	5.56 ( 6.33)		33.22 ( 9.90)	
Number of times since diagnosis daughter has taken days off from work as "sick", vacation, or personal days because the patient felt sick, had to be taken to a medical appointment, or needed errands run:		*		
None	8.83 ( 6.72)		38.50 (11.87)	
1-2	5.00 ( 3.11)		24.71 ( 3.30)	
3-4	9.57 ( 6.19)		42.43 (11.63)	
5+	7.87 ( 9.55)		35.07 (11.74)	

Table 43. Depression and Anxiety for Caregiving Daughters by Types of Burden (n≤58)  
 [continued]

	Depression Mean (S.D.)	State Anxiety Mean (S.D.)
Extent to which caregiving affected daughter's ability to concentrate on the job or to do her best at work:		
Not at all	8.00 ( 7.96)	37.86 (12.39)
To a small extent	5.67 ( 4.32)	33.00 (11.37)
To some extent	8.28 ( 6.57)	35.93 (11.54)
To a great extent	14.00 (12.98)	39.00 (15.46)
Does not apply	9.00 ( 8.82)	33.13 (13.28)
<b>Financial Burden</b>		
Extent that illness has caused daughter to pass up financial opportunities:		
Not at all	7.81 ( 7.27)	33.45 (11.99)
To a small extent	8.00 ( 3.65)	39.71 ( 9.81)
To some extent	14.67 (17.95)	37.67 (19.14)
To a great extent	14.00 (--)	51.00 (--)
Extent of financial changes in daughter's habits and lifestyle due to her caregiving:		
No changes at all	8.00 ( 6.25)	34.29 (11.56)
A few changes	8.67 (10.63)	35.56 (13.56)
Many changes	10.75 (14.93)	37.75 (18.82)
Seriousness of daughter's financial problems due to patient's illness:		
No financial problems	7.70 ( 5.94) ***	34.11 (11.37)
Not very serious	17.50 (27.75) ***	39.00 (26.87)
Somewhat serious	2.50 ( 2.12) ***	31.50 ( 4.95)
Very serious	33.00 (--) ***	65.00 (--)

\* p ≤ .05; \*\* p ≤ .01; \*\*\* p ≤ .001

Table 44. Comparison of Depressive Symptomatology by Sociodemographics (n≤60)

	CES-D <16 %	CES-D ≥16 %
<b>Patient/Disease Characteristics</b>		
Extent of Cancer *		
Local	74	29
Regional/Metastatic	26	71
Length of Time Since Diagnosis		
≤ 6 months	28	29
6 - 12 months	69	57
1 year+	4	14
Treatment		
Surgery	100	100
Radiation	49	43
Chemotherapy	31	57
<b>Daughter Sociodemographics</b>		
Age		
19 - 29	22	14
30 - 34	18	14
35 - 39	18	43
40 - 44	18	--
45 - 62	26	29
Ethnicity		
White, non-Hispanic	78	57
Black, non-Hispanic	4	--
Hispanic	16	43
Other	2	--
Marital Status		
Married	61	29
Widowed/Divorced/Separated	6	29
Never Married/Living with Partner	33	43
Education		
≤ High School	8	29
Some College	20	14
College Degree	35	57
Graduate/Professional Degree	37	--
Employment Status		
Not Employed	28	29
Employed Full-Time	18	14
Employed Part-Time	55	57

Table 44. Comparison of Depressive Symptomatology by Sociodemographics (n≤60)  
 [continued]

	CES-D <16 <u>%</u>	CES-D ≥16 <u>%</u>
<b>Number of Children</b>		
None	41	43
One	8	14
Two	31	43
Three or more	20	--
<b>Number in Household</b>		
One	14	43
Two	22	29
Three	18	14
Four	26	14
Five or more	22	--
<b>Daughter Lives with:</b>		
Spouse	63	43
Children	55	43
Patient	18	14

\* p ≤ .05

Table 45. Comparison of Depressive Symptomatology by Changes in the Network of the Relationship Between Mother and Daughter (n≤58)

	CES-D <16 %	CES-D ≥16 %
<b>Conflict in Relationship</b>		
Get upset or mad at each other:		
Worse	6	--
Same	70	43
Better	24	57
Disagree and quarrel:		
Worse	8	--
Same	68	86
Better	24	14
How much they argue:		
Worse	6	--
Same	74	71
Better	20	29
<b>Satisfaction in Relationship</b>		
Satisfied with relationship:		
Worse	4	14
Same	76	71
Better	20	14
Happy with the way things are between them:		
Worse	6	14
Same	78	86
Better	16	--
How good the relationship is:		
Worse	2	14
Same	70	57
Better	28	29
<b>Intimacy in Relationship</b>		
Tell each other everything:		
Worse	22	14
Same	70	86
Better	8	--
Share secrets and private feelings with each other:		
Worse	18	14
Same	70	71
Better	12	14
Talk about things they don't want other people to know:		
Worse	14	29
Same	74	71
Better	12	--

Table 45. Comparison of Depressive Symptomatology by Changes in the Network of the Relationship Between Mother and Daughter (n≤58) [continued]

	CES-D <16 %	CES-D ≥16 %
<b>Nurturance in the Relationship</b>		
Help with things they can't do themselves:		
Same	18	14
Better	82	86
Protect and look out for each other:		
Same	48	43
Better	52	57
Take care of other person: *		
Same	16	57
Better	84	43
<b>Admiration in the Relationship</b>		
Treated like they're admired and respected:		
Worse	2	--
Same	72	86
Better	26	14
Treated like they are good at many things: *		
Worse	2	29
Same	76	57
Better	22	14
How much like or approve of things other person does:		
Worse	2	14
Same	86	71
Better	12	14
<b>Relative Power in Relationship</b>		
Tells the other person what to do more often:		
Parent more	2	--
Same	52	100
Daughter more	46	--
Who tends to be the boss:		
Parent more	2	--
Same	68	57
Daughter more	30	43
Who tends to take charge and decide what's done:		
Parent more	2	--
Same	68	86
Daughter more	30	14

\* p ≤ .05

Table 46. Comparison of Depressive Symptomatology by Types of Burden (n≤58)

	CES-D <16 %	CES-D ≥16 %
<b>Social Burden</b>		
Extent that illness has reduced the amount of time daughter spends with friends, neighbors, and acquaintances:		
A great deal	10	14
Somewhat	12	14
Only a little	33	43
Not at all	45	29
Extent that illness has reduced daughter's outside activities such as hobbies and vacations:		
A great deal	12	14
Somewhat	8	14
Only a little	26	29
Not at all	55	43
Extent that illness has reduced daughter's time to take care of household duties and tasks:		
Often	16	14
Sometimes	26	14
Rarely	28	43
Never	31	29
Extent that illness has made it difficult to establish a daily routine and plan activities:		
Not at all	47	33
Only a little	28	50
Somewhat	16	17
A great deal	10	--
Extent that illness has reduced daughter's time with other family members:		
A great deal	2	--
Somewhat	12	29
Only a little	28	29
Not at all	59	43
<b>Time Burden</b>		
Has cut down on time spend doing regular daily activities due to her caregiving:	59	71
Feels that she has accomplished less than she would like due to her caregiving:	33	43

Table 46. Comparison of Depressive Symptomatology by Types of Burden (n≤58) [continued]

	CES-D <16 <u>%</u>	CES-D ≥16 <u>%</u>
Doesn't do regular activities as carefully as usual:	33	43
<b>Physical Burden</b>		
Amount of physical strain daughter experienced from caregiving since the diagnosis:		
A great deal of strain	8	14
A moderate amount of strain	31	14
A little strain	20	43
No strain	41	29
Extent caregiving has affected daughter's energy for her regular daily activities:		
A lot less energy	8	14
Somewhat less energy	4	--
A little less energy	37	43
No change in energy	51	43
<b>Financial Burden</b>		
Seriousness of daughter's financial problems * due to patient's illness:		
Very serious	--	14
Somewhat serious	4	--
Not very serious	2	14
No financial problems	94	71
Extent of financial changes in daughter's habits and lifestyle due to her caregiving:		
Many changes	6	14
Some changes	--	--
A few changes	16	14
No changes at all	78	71
Extent that illness has caused daughter to pass up financial opportunities		
To a great extent	2	--
To some extent	4	14
To a small extent	14	--
Not at all	80	86

Table 46. Comparison of Depressive Symptomatology by Types of Burden (n≤58) [continued]

	CES-D <16 <u>%</u>	CES-D ≥16 <u>%</u>
<b>Employment Burden</b>		
Extent to which caregiving affected daughter's ability to concentrate on the job or to do her best at work:		
Does not apply	28	29
To a great extent	8	14
To some extent	24	29
To a small extent	28	14
Not at all	12	14
Since diagnosis, daughter has come in late or left early because patient was sick, had to be taken to a medical appointment, or needed errands run:		
None	43	60
1 or 2	27	--
3 - 4	8	20
5 + times	22	20
Number of times since diagnosis daughter has taken days off from work as "sick", vacation, or personal days because the patient felt sick, had to be taken to a medical appointment, or needed errands run:		
None	28	40
1 or 2	19	--
3 - 4	17	20
5+ times	36	40

\* p ≤ .05

### **List of Appendices**

- A. Patient Contact Letter
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- E. Topic Guide
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## **APPENDIX A: Patient Contact Letter**

«Date\_Letter\_Sent»

«FirstName» «LastName»  
«Address»  
«City», «State» «ZipCode»

Dear Ms. «LastName»:

We are writing to ask you to participate in a research study that researchers at the Herbert Irving Comprehensive Cancer Center and Columbia University, Mailman School of Public Health are conducting. The name of the study is "Aging Families and Breast Cancer: Multigenerational Issues". Its purpose is to investigate the illness and treatment-related issues patients diagnosed with breast cancer and their familial caregivers are experiencing. We have spoken with Dr. «Doctor» about this study and *he/she* thinks you may be interested in taking part.

In a few days, a social worker on the study will be calling you to discuss the study further and answer any questions you might have. If you do not want to be called, check-off the "Do not contact" box on the enclosed postcard and mail it back to our office. If you are interested in this study, the social worker will ask you a few, brief questions about yourself and your illness to see if you and your familial caregiver are eligible to participate in the study. If you are, both of you will be asked to complete an interview. The interview will be conducted by a member of our research team. In this interview we will ask you about your illness and needs for assistance. We will also ask you some background questions about yourself. You can choose not to answer any question. Your interview will be conducted by telephone at a time that is convenient to you. It will take about 40 minutes. We will also be interviewing your familial caregiver about her care giving experiences and how your illness and its treatment has affected her.

What you tell us in this interview will be kept strictly confidential. It will only be used for the present study and the information you provide will only be seen by the investigators carrying out the research. All study data will be assigned a unique code number and kept in locked file cabinets in our research offices. Your doctor will not know that you agreed to participate in the study. This study has been funded by the NYS Breast Cancer Research and Education Fund, and by the Department of Defense. Representatives from the U.S. Army Medical Research and Materiel Command are eligible to inspect the records of this research as part of their responsibilities to protect human subjects in research.

If you decide not to participate in this study, your decision will in no way affect the medical or other services you are receiving now or in the future. If you do decide to participate, you can decide to stop participating at any time. There will be no penalty or loss of benefits to which you are entitled. There are no physical risks or cost to you for participating in the study. You will not receive any payment for the interview. Talking with the research clinician may cause you to confront some sensitive feelings and issues related to your illness and its treatment. For this reason, the interviewer is an experienced clinician who has been trained to address any such distress. Although you may not benefit directly from this study, we feel that what you and your familial caregiver will tell us

about your experiences will help other patients and their families in the future.

If at anytime you need any additional information, you may call me (Victoria H. Raveis, Ph.D.) at (212) 304-5566. The solicitation of subjects into this study has been approved by the Columbia Presbyterian Medical Center Institutional Review Board. If you have any questions about your rights as a research subject, you can call the Institutional Review Board at (212) 305-5883 for information.

The choice to participate in this study is yours. You are in a position to make a decision if you understand what you have read in this letter about the study. Your participation in the research interview will be regarded as evidence of your consent to participate. You will not be asked to sign a consent form. If you agree to the interview, you still have a right to stop at any time.

Sincerely,

Victoria H. Raveis, Ph.D.  
Associate Professor of Sociomedical Sciences

cc: Dr. «Doctor»

---

## **APPENDIX B: Caregiver Daughter Contact Letter**

*Date*

*Caregiver's Name*  
*Street Address*  
*City, State, Zip Code*

Dear Ms./Mrs. *Caregiver's Name*:

We are writing to ask you to participate in a research study that researchers at the Herbert Irving Comprehensive Cancer Center and Columbia University, Mailman School of Public Health are conducting. The name of the study is "Aging Families and Breast Cancer: Multigenerational Issues". Its purpose is to investigate the illness and treatment-related issues patients diagnosed with breast cancer and their familial caregivers are experiencing. We have spoken with your relative about this study and she has told us how to contact you.

In a few days a social worker on the study will be calling you to tell you more about this study and answer any questions you may have. If you decide to participate in this study we are asking you to participate in a two and one-half hour face-to-face research meeting with a research clinician. This research meeting will be scheduled at your convenience. It will be held at our research offices at 100 Haven Avenue, about three blocks away from the hospital.

In the first part of the meeting you will be asked to answer a questionnaire that will contain questions about your relative's illness, treatment experiences and needs for assistance. We will also ask you about your care giving and some background questions about yourself. In the second part of the research meeting, we will ask you to tell us in greater detail about how your relative's illness and its treatment has impacted on your life. We will also ask you about other illness-related issues and concerns you may have. With your permission we will tape record this part so that it can be typed up and analyzed.

If you decide not to participate, your decision will in no way affect the medical or other services your relative is receiving now or in the future. The choice to participate in this study is yours. You are in a position to make a decision if you understand what you have read in this letter about the study. If you agree to the interview, you still have a right to stop at any time.

If at anytime you need any additional information, you may call me (Victoria H. Raveis, Ph.D.) at (212) 304-5566. The solicitation of subjects into this study has been approved by the Columbia Presbyterian Medical Center Institutional Review Board. If you have any questions about your rights as a research subject, you can call the Institutional Review Board at (212) 305-5883 for information.

Sincerely,

Victoria H. Raveis, Ph.D.  
Associate Professor of Sociomedical Sciences

## **APPENDIX C: Patient Interview**

CODED \_\_\_\_\_

Time Started  
\_\_\_\_\_ am/pm

ENTERED \_\_\_\_\_

Time Ended  
\_\_\_\_\_ am/pm

VERIFIED \_\_\_\_\_

**Aging Families and Breast Cancer:  
Multigenerational Issues**

**Patient Interview**

**ID#** \_\_\_\_\_

TIME BEGUN:

\_\_\_\_ / \_\_\_\_ a.m./p.m.

**SOCIODEMOGRAPHIC QUESTIONS**

1. What is your date of birth?

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
month day year

BRPS1MO  
BRPS1DA  
BRPS1YR

2. What is the highest level of schooling you have completed?

Eighth grade or less .....	1
Some High School .....	2
High School Graduate or GED .....	3
Some College.....	4
Associate's Degree .....	5
Technical or vocational school .....	6
College Degree .....	7
Some graduate school.....	8
Graduate or professional degree .....	9

BRPS2

3. How would you describe yourself? Would you say you are...

White .....	1	(ASK A)
Black/African American.....	2	(ASK A)
Asian or Pacific Islander .....	3	
American Indian/Alaskan native .....	4	
Other (SPECIFY _____) .....	5	(ASK A)

BRPS3

A. Are you of Hispanic origin or descent?

Yes.....	1	(ASK B)
No.....	2	

BRPS3A

B. Do you consider yourself to be...

Puerto Rican .....	1
Dominican .....	2
Cuban .....	3
Mexican .....	4
Ecuadorean .....	5
Columbian .....	6
Spanish or European.....	7
Something else (SPECIFY: _____) .....	10

BRPS3B

4. Are you currently employed, not employed, on disability, out on sick leave, or something else?

BRPS4

Employed .....	1	(ASK A)
Disability .....	2	(ASK C)
Sick Leave .....	3	(ASK C)
Not employed, laid off, looking for work .....	4	(ASK B)
Retired .....	5	(ASK C)
In school and <u>not</u> working .....	6	(ASK B)
Keeping house .....	7	(ASK B)
Other (SPECIFY) _____	8	(ASK B)

A. (IF EMPLOYED) About how many hours do you work in an average week?

BRPS4A

\_\_\_\_\_ # of hours      **IF LESSTHAN 35 HOURS GO TO D.**  
**IF 35+ GO TO Q.5.**

B. Have you ever held a job which lasted for six months or longer?

BRPS4B

Yes.....	1
No.....	2

(IF NO, GO TO Q. 8)

C. In what month and year did you last work?

BRPS4CMO  
BRPS4CYR

\_\_\_\_\_ / \_\_\_\_\_  
month      year

D. (IF WORKING PART-TIME OR NOT WORKING) Are you (working part-time/not working) because of your illness?

BRPS4D

Yes.....	1
No.....	2

5. What kind of work (do)(did) you do? That is, what (is)(was) your job called? (PROBE, IF NECESSARY) What (do)(did) you actually do in that job? What (are) were some of your main duties or responsibilities?

BRPS5

Occupation: \_\_\_\_\_

Job Title: \_\_\_\_\_

Duties: \_\_\_\_\_

A. What kind of company or industry is that? What do/did they do or make at the place where you work(ed)?  
\_\_\_\_\_  
\_\_\_\_\_

6. Are/Were you self employed in your own business, practice, or working without pay in a family business (on your main job)?

BRPS6

Yes, self employed .....	1
No, work for someone else .....	2

7. (What is/When you were working, what was) your annual salary before taxes from your job?  
I'll start reading off a list of income ranges; just stop me when I reach the category that includes your income.

BRPS7

\$5,000 or less.....	1	
\$5,001 - \$10,000.....	2	
\$10,001 - \$15,000.....	3	
\$15,001 - \$20,000.....	4	
\$20,001 - \$25,000.....	5	
\$25,001 - \$30,000.....	6	
\$30,001 - \$40,000.....	7	
\$40,001 - \$50,000.....	8	
\$50,001 - \$60,000.....	9	
\$60,001 - \$70,000 .....	10	
\$70,001 - \$80,000.....	11	
\$80,001 - \$90,000.....	12	
\$90,001 - \$100,000.....	13	
\$100,001 or more .....	14	
Does not know.....	97	(ASK A)
Refuses to answer .....	99	(ASK A)

A. Can you tell me if it was...

BRPS7A

Less than \$25,000 a year or .....	1
More than \$25,000 a year .....	2
DOESN'T KNOW; REFUSED .....	3

8. What is your current marital status?

BRPS8

Married .....	1	(ASK A)
IF VOLUNTEERED: Living with a partner .....	2	(ASK A)
Divorced .....	3	
Separated .....	4	
Widowed .....	5	
Never Married .....	6	

A. How long have you been (married/living together)?

BRPS8A

\_\_\_\_\_ number of years

9. How many children do you have?

BRPS9

\_\_\_\_\_ number of children

10. Could you please tell me who lives with you in your household? **IF R. LIVES ALONE GO TO Q.**  
**11. (ASK A-C FOR EACH PERSON IN HOUSEHOLD) (NOTE: IF HOUSEHOLD COMPOSITION HAS CHANGED FROM THE USUAL, CODE FOR COMPOSITION IN THE LAST MONTH), PROBE: Anyone else?**

A. What is their relationship to you?	B. Sex	Male	Female	C. What was his/her age on his/her last birthday?	
Pers. 1. _____	1	2	_____	_____	BRPS10R1 BRPS10S1 BRPS10A1
Pers. 2. _____	1	2	_____	_____	BRPS10R2 BRPS10S2 BRPS10A2
Pers. 3. _____	1	2	_____	_____	BRPS10R3 BRPS10S3 BRPS10A3
Pers. 4. _____	1	2	_____	_____	BRPS10R4 BRPS10S4 BRPS10A4
Pers. 5. _____	1	2	_____	_____	BRPS10R5 BRPS10S5 BRPS10A5
Pers. 6. _____	1	2	_____	_____	BRPS10R6 BRPS10S6 BRPS10A6
Pers. 7. _____	1	2	_____	_____	BRPS10R7 BRPS10S7 BRPS10A7
Pers. 8. _____	1	2	_____	_____	BRPS10R8 BRPS10S8 BRPS10A8
11. So, <i>including yourself</i> , the total number of people living in your household is:	_____			BRPS11	

12. What was the total income, *during the last year*, of everyone who lived in your household? Total (gross income includes things like salary, disability income, social security, interest, and so on. I'll start reading off a list of income ranges; just stop me when I reach the category that includes your income.

BRPS12

\$5,000 or less.....	1
\$5,001 - \$10,000.....	2
\$10,001 - \$15,000.....	3
\$15,001 - \$20,000.....	4
\$20,001 - \$25,000.....	5
\$25,001 - \$30,000.....	6
\$30,001 - \$40,000.....	7
\$40,001 - \$50,000.....	8
\$50,001 - \$60,000.....	9
\$60,001 - \$70,000 .....	10
\$70,001 - \$80,000.....	11
\$80,001 - \$90,000.....	12
\$90,001 - \$100,000.....	13
\$100,001 or more .....	14

Does not know.....	97	(ASK A)
Refuses to answer .....	99	(ASK A)

A. Can you tell me if it was...

BRPS12A

Less than \$25,000 a year or .....	1
More than \$25,000 a year .....	2
DOESN'T KNOW; REFUSED .....	3

### NETWORK OF RELATIONSHIPS (Abbreviated)

We are interested in how illness changes relationships. In this next series of items we ask about how your relationship with your familial caregiver has been *since your diagnosis and* how it was *prior to your illness*

		<u>Not at all or a little</u>	<u>Somewhat</u>	<u>Very</u>	<u>Extremely</u>	<u>The most</u>	<u>DNA</u>	
1.	How much do you and your familial caregiver get upset or mad at each other?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR1A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR1B
2.	How satisfied are you with your relationship with your familial caregiver?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR2A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR2B
3.	How much do you tell your familial caregiver everything?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR3A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR3B
4.	How much do you help your familial caregiver with things she can't do by herself?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR4A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR4B
5.	How much does your familial caregiver treat you like you're admired and respected?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR5A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR5B
6.	How much do you and your familial caregiver disagree and quarrel?							
a.	since the diagnosis	1	2	3	4	5	8	BRPNR6A
b.	prior to the diagnosis	1	2	3	4	5	8	BRPNR6B

		Not at all or a little	Somewhat	Very	Extremely	The most	DNA	
7.	How happy are you with the way things are between you and your familial caregiver?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR7A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR7B
8.	How much do you share your secrets and private feelings with your familial caregiver?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR8A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR8B
9.	How much do you protect and look out for your familial caregiver?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR9A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR9B
10.	How much does your familial caregiver treat you like you're good at many things?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR10A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR10B
11.	How much do you and your familial caregiver argue with each other?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR11A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR11B
12.	How good is your relationship with your familial caregiver?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR12A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR12B
13.	How much do you talk to your familial caregiver about things that you don't want others to know?							
	a. since the diagnosis	1	2	3	4	5	8	BRPNR13A
	b. prior to the diagnosis	1	2	3	4	5	8	BRPNR13B

	<u>Not at all or a little</u>	<u>Somewhat</u>	<u>Very</u>	<u>Extremely</u>	<u>The most</u>	<u>DNA</u>	
14. How much do you take care of your familial caregiver?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR14A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR14B
15. How much does your familial caregiver like or approve of the things you do?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR15A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR15B
16. How close is your relationship with your familial caregiver?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR16A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR16B
	<b>Familial Caregiver</b>						
	<u>almost always does</u>	<u>Familial Caregiver often does</u>	<u>About the same</u>	<u>I often do</u>	<u>I almost always do</u>	<u>DNA</u>	
17. Who tells the other person what to do more often, you or your familial caregiver?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR17A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR17B
18. Between you and your familial caregiver who tends to be the BOSS in this relationship?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR18A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR18B
19. In your relationship with your familial caregiver who tends to take charge and decide what should be done?							
a. since the diagnosis	1	2	3	4	5	8	BRPNR19A
b. prior to the diagnosis	1	2	3	4	5	8	BRPNR19B

## **FILIAL OBLIGATION**

In this next series of questions, we will be asking you your opinions about help in the home

1. Married children should live close to parents to provide care. Do you . . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO1

2. Children should not be expected to do tasks for their parents. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO2

3. Parents should expect adult children to assist them. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO3

4. It is a child's duty to assist parents. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO4

5. It is preferable to pay a professional for assistance with caregiving. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO5

6. Paying for professional help means a relative is not taking responsibility. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO6

7. It is better to give up a job to provide care than to pay a professional. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree .....	3
Somewhat disagree .....	2
Strongly disagree .....	1

BRPFO7

## DAILY LIVING ACTIVITIES

As a result of illness, people often find that they have to change their routines. For each of the activities I am going to read to you, please tell me if you do it yourself, or you get some help with it, or whether someone did it for you even before your illness (**PROBE WHEN NECESSARY TO DETERMINE THAT HELP IS ILLNESS-RELATED**).

1. Who does your light housekeeping such as dusting, washing dishes and making beds? Do you do it yourself, get some help with it, or does someone do it for you?

BRPD1

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness .....	3	(ASK A & B)
Other has always done it (not illness-related) .....	4	(ASK A)
Not done .....	5	(ASK B)

A. Who helps? (**CIRCLE ALL THAT APPLY**)

Caregiver .....	0
Spouse .....	1
Daughter.....	3
Son .....	4
Daughter-in-law .....	5
Son-in-law .....	6
Brother.....	7
Sister.....	8
Other relative (WHO: _____) .....	9
Friend .....	10
Nurse, health aide.....	11
Co-worker/employee.....	12
Therapist.....	13
Social Worker.....	14
Doctor/Psychiatrist.....	15
Other (WHO: _____) .....	16

BRPD1A1  
BRPD1A2  
BRPD1A3  
BRPD1A4  
BRPD1A5

B. Do you need (more) help? (**IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?**)

BRPD1B

Yes .....	1
No.....	2

2. Who does your heavy housekeeping such as mopping, vacuuming, laundry or cleaning the bathroom? Do you do it yourself, do you get some help with it, or does someone do it for you?

BRPD2

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness .....	3	(ASK A & B)
Other has always done it (not illness-related) .....	4	(ASK A)
Not done .....	5	(ASK B)

**A. Who helps? (CIRCLE ALL THAT APPLY)**

Caregiver .....	0	BRPD2A1
Spouse .....	1	BRPD2A2
Daughter.....	3	BRPD2A3
Son .....	4	BRPD2A4
Daughter-in-law .....	5	BRPD2A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist .....	15	
Other (WHO: _____)	16	

**B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)**

BRPD2B

Yes.....	1	
No.....	2	

**3. Who does your cooking and meal preparation? Do you do it yourself, do you get some help with it, or does someone do it for you?**

BRPD3

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related) .....	4	(ASK A)
Not done.....	5	(ASK B)

**A. Who helps? (CIRCLE ALL THAT APPLY)**

Caregiver .....	0	BRPD3A1
Spouse .....	1	BRPD3A2
Daughter.....	3	BRPD3A3
Son .....	4	BRPD3A4
Daughter-in-law .....	5	BRPD3A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist .....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)	BRPD3B
Yes.....1	
No.....2	
4. Who does your shopping for clothes and household items? Do you do it yourself, do you get some help with it, or does someone do it for you?	BRPD4
Does it alone .....1	(ASK B)
Has help in doing this activity.....2	(ASK A & B)
Someone is doing this activity for patient due to illness.....3	(ASK A & B)
Other has always done it (not illness-related).....4	(ASK A)
Not done .....5	(ASK B)
A. Who helps? (CIRCLE ALL THAT APPLY)	
Caregiver .....0	BRPD4A1
Spouse .....1	BRPD4A2
Daughter.....3	BRPD4A3
Son .....4	BRPD4A4
Daughter-in-law .....5	BRPD4A5
Son-in-law.....6	
Brother.....7	
Sister.....8	
Other relative (WHO: _____) .....9	
Friend .....10	
Nurse, health aide.....11	
Co-worker/employee.....12	
Therapist.....13	
Social Worker.....14	
Doctor/Psychiatrist.....15	
Other (WHO: _____).....16	
B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)	BRPD4B
Yes.....1	
No.....2	
5. Who does your grocery shopping? Do you do it yourself, do you get some help with it, or does someone do it for you?	BRPD5
Does it alone .....1	(ASK B)
Has help in doing this activity.....2	(ASK A & B)
Someone is doing this activity for patient due to illness.....3	(ASK A & B)
Other has always done it (not illness-related).....4	(ASK A)
Not done .....5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD5A1
Spouse .....	1	BRPD5A2
Daughter.....	3	BRPD5A3
Son .....	4	BRPD5A4
Daughter-in-law .....	5	BRPD5A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD5B

Yes.....	1
No .....	2

6. Do you bathe and shower by yourself or does someone help you?

BRPD6

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related) .....	4	(ASK A)
Not done .....	5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD6A1
Spouse .....	1	BRPD6A2
Daughter.....	3	BRPD6A3
Son .....	4	BRPD6A4
Daughter-in-law .....	5	BRPD6A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD6B

Yes ..... 1  
No ..... 2

7. Do you perform any home health care tasks, such as keeping track of medications or changing your dressings by yourself, do you get some help with this, or does someone do it for you?

BRPD7

Does it alone ..... 1 (ASK B)  
Has help in doing this activity ..... 2 (ASK A & B)  
Someone is doing this activity for patient due to illness ..... 3 (ASK A & B)  
Other has always done it (not illness-related) ..... 4 (ASK A)  
Not done ..... 5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver ..... 0  
Spouse ..... 1  
Daughter ..... 3  
Son ..... 4  
Daughter-in-law ..... 5  
Son-in-law ..... 6  
Brother ..... 7  
Sister ..... 8  
Other relative (WHO: \_\_\_\_\_) ..... 9  
Friend ..... 10  
Nurse, health aide ..... 11  
Co-worker/employee ..... 12  
Therapist ..... 13  
Social Worker ..... 14  
Doctor/Psychiatrist ..... 15  
Other (WHO: \_\_\_\_\_) ..... 16

BRPD7A1  
BRPD7A2  
BRPD7A3  
BRPD7A4  
BRPD7A5

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD7B

Yes ..... 1  
No ..... 2

8. Do you get dressed by yourself, or does someone help you?

BRPD8

Does it alone ..... 1 (ASK B)  
Has help in doing this activity ..... 2 (ASK A & B)  
Someone is doing this activity for patient due to illness ..... 3 (ASK A & B)  
Other has always done it (not illness-related) ..... 4 (ASK A)  
Not done ..... 5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD8A1
Spouse .....	1	BRPD8A2
Daughter .....	3	BRPD8A3
Son .....	4	BRPD8A4
Daughter-in-law .....	5	BRPD8A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD8B

Yes.....	1
No .....	2

9. Are you able to use the toilet by yourself, or does someone help you?

BRPD9

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related).....	4	(ASK A)
Not done.....	5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD9A1
Spouse .....	1	BRPD9A2
Daughter .....	3	BRPD9A3
Son .....	4	BRPD9A4
Daughter-in-law .....	5	BRPD9A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD9B

Yes ..... 1  
No ..... 2

10. Do you get in and out of a bed or chair by yourself, or does someone help you?

BRPD10

Does it alone ..... 1 (ASK B)  
Has help in doing this activity ..... 2 (ASK A & B)  
Someone is doing this activity for patient due to illness ..... 3 (ASK A & B)  
Other has always done it (not illness-related) ..... 4 (ASK A)  
Not done ..... 5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD10A1
Spouse .....	1	BRPD10A2
Daughter .....	3	BRPD10A3
Son .....	4	BRPD10A4
Daughter-in-law .....	5	BRPD10A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____) .....	9	
Friend .....	10	
Nurse, health aide .....	11	
Co-worker/employee .....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____) .....	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD10B

Yes ..... 1  
No ..... 2

11. When you travel to your medical appointments at the hospital, do you usually go by yourself or does someone go with you?

BRPD11

Does it alone ..... 1 (ASK B)  
Has help in doing this activity ..... 2 (ASK A & B)  
Someone is doing this activity for patient due to illness ..... 3 (ASK A & B)  
Other has always done it (not illness-related) ..... 4 (ASK A)  
Not done ..... 5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD11A1
Spouse .....	1	BRPD11A2
Daughter .....	3	BRPD11A3
Son .....	4	BRPD11A4
Daughter-in-law .....	5	BRPD11A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

Yes.....	1
No.....	2

12. When you travel for other purposes such as work, visiting, or errands, do you usually go by yourself or does someone go with you?

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related).....	4	(ASK A)
Not done.....	5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD12A1
Spouse .....	1	BRPD12A2
Daughter .....	3	BRPD12A3
Son .....	4	BRPD12A4
Daughter-in-law .....	5	BRPD12A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____)	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____)	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

Yes.....	1
No.....	2

13. Do you fill out forms such as insurance claims, medical forms, and applications for financial benefits yourself, do you get some help with it or does someone do it for you?

BRPD13

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related).....	4	(ASK A)
Not done.....	5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0
Spouse .....	1
Daughter .....	3
Son .....	4
Daughter-in-law .....	5
Son-in-law .....	6
Brother.....	7
Sister.....	8
Other relative (WHO: _____) .....	9
Friend .....	10
Nurse, health aide.....	11
Co-worker/employee.....	12
Therapist.....	13
Social Worker.....	14
Doctor/Psychiatrist.....	15
Other (WHO: _____) .....	16

BRPD13A1  
BRPD13A2  
BRPD13A3  
BRPD13A4  
BRPD13A5

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD13B

Yes .....	1
No.....	2

14. Do you handle your banking by yourself; that is, make deposits and withdrawals, pay bills, write checks, maintain a checking account, or do you get some help with it, or does someone do it for you?

BRPD14

Does it alone .....	1	(ASK B)
Has help in doing this activity.....	2	(ASK A & B)
Someone is doing this activity for patient due to illness.....	3	(ASK A & B)
Other has always done it (not illness-related).....	4	(ASK A)
Not done.....	5	(ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD14A1
Spouse .....	1	BRPD14A2
Daughter .....	3	BRPD14A3
Son .....	4	BRPD14A4
Daughter-in-law .....	5	BRPD14A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____) .....	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____) .....	16	

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPD14B

Yes .....	1
No .....	2

15. Do you need help or are you getting help in obtaining information about your illness or treatment?

BRPD15

Has no need .....	1
Has help in doing this activity.....	2
Needs help .....	3

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....	0	BRPD15A1
Spouse .....	1	BRPD15A2
Daughter .....	3	BRPD15A3
Son .....	4	BRPD15A4
Daughter-in-law .....	5	BRPD15A5
Son-in-law .....	6	
Brother.....	7	
Sister.....	8	
Other relative (WHO: _____) .....	9	
Friend .....	10	
Nurse, health aide.....	11	
Co-worker/employee.....	12	
Therapist.....	13	
Social Worker.....	14	
Doctor/Psychiatrist.....	15	
Other (WHO: _____) .....	16	

B. Do you need (more) help?

BRPD15B

Yes .....	1
No .....	2

16. Do you need or are you getting illness-related financial counseling or advice?

BRPD16

Has no need .....1  
Getting counseling .....2  
Needs counseling .....3

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....0  
Spouse .....1  
Daughter .....3  
Son .....4  
Daughter-in-law .....5  
Son-in-law .....6  
Brother .....7  
Sister .....8  
Other relative (WHO: \_\_\_\_\_) .....9  
Friend .....10  
Nurse, health aide .....11  
Co-worker/employee .....12  
Therapist .....13  
Social Worker .....14  
Doctor/Psychiatrist .....15  
Other (WHO: \_\_\_\_\_) .....16

BRPD16A1  
BRPD16A2  
BRPD16A3  
BRPD16A4  
BRPD16A5

B. Do you need (more) help?

BRPD16B

Yes .....1  
No .....2

17. Do you need or are you getting illness-related legal counseling or advice such as power of attorney?

BRPD17

Has no need .....1  
Getting counseling .....2  
Needs counseling .....3

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

Caregiver .....0  
Spouse .....1  
Daughter .....3  
Son .....4  
Daughter-in-law .....5  
Son-in-law .....6  
Brother .....7  
Sister .....8  
Other relative (WHO: \_\_\_\_\_) .....9  
Friend .....10  
Nurse, health aide .....11  
Co-worker/employee .....12  
Therapist .....13  
Social Worker .....14  
Doctor/Psychiatrist .....15  
Other (WHO: \_\_\_\_\_) .....16

BRPD17A1  
BRPD17A2  
BRPD17A3  
BRPD17A4  
BRPD17A5

B. Do you need (more) help?

BRPD17B

Yes .....1  
No .....2

### ILLNESS PREDICTABILITY

1. I usually know when I am going to have a good or bad day. Do you. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRPIP1

2. It is clear to me when my illness is getting better or worse. Do you. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRPIP2

3. I can generally predict the course of my illness. Do you. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRPIP3

4. My physical distress is predictable. Do you. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRPIP4

### ILLNESS CONTROL

5. How much personal control do you think you have over the amount of fatigue you experience from day to day? Would you say you have. . .

BRPIC5

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY.....	8

6. How much personal control do you think you have over the amount of discomfort you experience from day to day? Would you say you have. . .

BRPIC6

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY.....	8

7. How much personal control do you think you have over the amount of immobility you experience from day to day? Would you say you have...

BRPIC7

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

8. How much personal control do you think you have over the amount of pain you experience from day to day? Would you say you have...

BRPIC8

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

9. How much personal control do you believe you have over the long-term course of your illness, (that is, whether it will improve or at least not worsen in the future)? Would you say you have...

BRPIC9

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

10. How much personal control do you think you have over the medical care and treatment of your illness? Would you say you have...

BRPIC10

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

### CES-D SCALE

I will now read you a list of the ways you might have felt or behaved *during the past week*. As I read each statement, please tell me the category which best describes how often you have felt this way *during the past week*.

Rarely Or None Of The Time (Less Than <u>1 Day</u> )	Some Or A Little Of The Time ( <u>1-2 Days</u> )	Occasionally Or A Moderate Amount of Time ( <u>3-4 Days</u> )	Most Or All Of The Time ( <u>5-7 Days</u> )
--	---	--	--

***During the past week:***

1. I was bothered by things that usually don't bother me. Would you say you felt this way...	1	2	3	4	BRPCES1
2. I did not feel like eating; my appetite was poor	1	2	3	4	BRPCES2
3. I felt that I could not shake off the blues even with help from my friends or family	1	2	3	4	BRPCES3
4. I felt that I was just as good as other people	4	3	2	1	BRPCES4
5. I had trouble keeping my mind on what I was doing	1	2	3	4	BRPCES5
6. I felt depressed	1	2	3	4	BRPCES6
7. I felt that everything I did was an effort	1	2	3	4	BRPCES7
8. I felt hopeful about the future	4	3	2	1	BRPCES8
9. I thought my life had been a failure	1	2	3	4	BRPCES9
10. I felt fearful	1	2	3	4	BRPCES10
11. My sleep was restless	1	2	3	4	BRPCES11
12. I was happy	4	3	2	1	BRPCES12
13. I talked less than usual	1	2	3	4	BRPCES13
14. I felt lonely	1	2	3	4	BRPCES14
15. People were unfriendly	1	2	3	4	BRPCES15
16. I enjoyed life	4	3	2	1	BRPCES16
17. I had crying spells	1	2	3	4	BRPCES17

	Rarely Or None Of The Time (Less Than <u>1 Day</u> )	Some Or A Little of The Time (1-2 Days)	Occasionally Or A Moderate Amount of Time (3-4 Days)	Most Or All Of The Time (5-7 Days)	
18. I felt sad	1	2	3	4	BRPCES18
19. I felt that people disliked me	1	2	3	4	BRPCES19
20. I could not get "going"	1	2	3	4	BRPCES20
21. I felt alone or cut off from other people	1	2	3	4	BRPCES21

**STATE-TRAIT ANXIETY (MODIFIED - STATE ONLY)**

I am going to read you a number of statements which people have used to describe themselves. As I read each statement, please give me the answer which seems to describe how you feel *right now*.

	<u>Not at All</u>	<u>Somewhat</u>	<u>Moderately So</u>	<u>Very Much So</u>	
1. I feel calm. Would you say this describes how you feel...	1	2	3	4	BRPST1
2. I feel secure	1	2	3	4	BRPST2
3. I am tense	1	2	3	4	BRPST3
4. I feel strained	1	2	3	4	BRPST4
5. I feel at ease	1	2	3	4	BRPST5
6. I feel upset	1	2	3	4	BRPST6
7. I am presently worrying over possible misfortunes	1	2	3	4	BRPST7
8. I feel satisfied	1	2	3	4	BRPST8
9. I feel frightened	1	2	3	4	BRPST9
10. I feel comfortable	1	2	3	4	BRPST10
11. I feel self-confident	1	2	3	4	BRPST11
12. I feel nervous	1	2	3	4	BRPST12
13. I feel jittery	1	2	3	4	BRPST13
14. I feel indecisive	1	2	3	4	BRPST14
15. I feel relaxed	1	2	3	4	BRPST15
16. I feel content	1	2	3	4	BRPST16
17. I feel worried	1	2	3	4	BRPST17
18. I feel confused	1	2	3	4	BRPST18
19. I feel steady	1	2	3	4	BRPST19
20. I feel pleasant	1	2	3	4	BRPST20

**Thank you for your cooperation. Is there anything else you'd like to comment on that we have not covered in this interview?**

TIME ENDED:

\_\_\_\_\_ / \_\_\_\_\_ a.m./p.m.  
hour minutes

BRPHR  
BRPMN

INTERVIEWER REMARKS

1. Did respondent experience or exhibit emotional or psychological problems during the interview?

Yes ..... 1 (ANSWER A)  
No ..... 2

BRPR1

A. What was the problem? \_\_\_\_\_  
\_\_\_\_\_

BRPR1A1  
BRPR1A2  
BRPR1A3

2. Were there any other problems during the interview?

Yes ..... 1 (ANSWER A)  
No ..... 2

BRPR2

A. What was the problem? \_\_\_\_\_  
\_\_\_\_\_

BRPR2A1  
BRPR2A2  
BRPR2A3

3. Was interview conducted in English or Spanish?

English ..... 1 (ANSWER A)  
Spanish ..... 2

BRPR3

A. How much trouble does respondent have understanding English?

None ..... 1  
Some ..... 2  
A great deal ..... 3

BRPR3A

4. Regardless of whether or not interview was completed in one session, did the respondent *want to* terminate interview before interview was finished?

Yes ..... 1 (ANSWER A)  
No ..... 2

BRPR4

A. At what points and why?  
\_\_\_\_\_  
\_\_\_\_\_

BRPR4A1  
BRPR4A2  
BRPR4A3

5. Did respondent need to complete interview over two or more sessions?

Yes ..... 1 (ANSWER A)  
No ..... 2

BRPR5

A. Reasons given for needing to break up interview \_\_\_\_\_  
\_\_\_\_\_

BRPR5A1  
BRPR5A2  
BRPR5A3

6. Date interview started:

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
(mo) (da) (yr)

BRPR6MO  
BRPR6DA  
BRPR6YR

7. Date interview completed:

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
(mo) (da) (yr)

BRPR7MO  
BRPR7DA  
BRPR7YR

8. Number of interviewing sessions needed to complete interview:

One ..... 1  
Two ..... 2  
Three ..... 3  
Four ..... 4

BRPR8

9. Name and ID of interviewer:

NAME \_\_\_\_\_ I.D. \_\_\_\_\_

BRPR9

10. Total time spent interviewing:

\_\_\_\_ / \_\_\_\_  
hours minutes

BRPR10

11. Proxy questionnaire was answered by:

Caregiving Daughter ..... 1  
Patient's Spouse ..... 2  
Other Daughter of Patient ..... 3  
Patient's Son ..... 4  
Other Relative (Specify \_\_\_\_\_) ..... 5  
**NOT APPLICABLE; Patient completed questionnaire herself ..... 8**

BRPR11

**Interviewer Comments and observations not otherwise specified:**

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## **APPENDIX D: Caregiver Daughter Interviews**

CODED \_\_\_\_\_

Time Started  
\_\_\_\_\_ am/pm

ENTERED \_\_\_\_\_

Time Ended  
\_\_\_\_\_ am/pm

VERIFIED \_\_\_\_\_

**Aging Families and Breast Cancer:  
Multigenerational Issues**

**Caregiving Relative Interview**

**ID#** \_\_\_\_\_

/    a.m./p.m.SOCIODEMOGRAPHIC QUESTIONS

1. What is your date of birth?

   /    /     
month day yearBRCS1MO  
BRCS1DA  
BRCS1YR

2. What is the highest level of schooling you have completed?

Eighth grade or less .....	1
Some High School.....	2
High School Graduate or GED.....	3
Some College .....	4
Associate's Degree.....	5
Technical or vocational school.....	6
College Degree.....	7
Some graduate school.....	8
Graduate or professional degree.....	9

BRCS2

3. How would you describe yourself? Would you say you are...

White .....	1
Black/African American.....	2
Asian or Pacific Islander .....	3
American Indian/Alaskan native .....	4
Other (SPECIFY <u>                  </u> ) .....	5

BRCS3

A. Are you of Hispanic origin or descent?

Yes.....	1
No .....	2

BRCS3A

B. Do you consider yourself to be...

Puerto Rican .....	1
Dominican .....	2
Cuban .....	3
Mexican.....	4
Ecuadorean .....	5
Columbian .....	6
Spanish or European.....	7
Something else (SPECIFY: <u>                  </u> ) .....	10

BRCS3B

4. Are you currently employed, not employed, on disability, out on sick leave, or something else?

BRCS4

Employed .....	1	(ASK A)
Disability .....	2	(ASK C)
Sick Leave .....	3	(ASK C)
Not employed, laid off, looking for work.....	4	(ASK B)
Retired .....	5	(ASK C)
In school and <u>not</u> working .....	6	(ASK B)
Keeping house.....	7	(ASK B)
Other (SPECIFY _____)	8	(ASK B)

A. (IF EMPLOYED) About how many hours do you work in an average week?

BRCS4A

\_\_\_\_\_ # of hours     **IF LESSTHAN 35 HOURS GO TO D.**  
**IF 35+ GO TO Q.5.**

B. Have you ever held a job which lasted for six months or longer?

BRCS4B

Yes.....	1
No .....	2

(IF NO, GO TO Q. 8)

C. In what month and year did you last work?

BRCS4CMO  
BRCS4CYR

\_\_\_\_\_ / \_\_\_\_\_  
month      year

D. (IF WORKING PART-TIME OR NOT WORKING) Are you (working part-time/not working) because of your relative's illness?

BRCS4D

Yes.....	1
No.....	2

5. What kind of work (do)(did) you do? That is, what (is)(was) your job called? (PROBE, IF NECESSARY) What (do)(did) you actually do in that job? What (are) were some of your main duties or responsibilities?

BRCS5

Occupation: \_\_\_\_\_

Job Title: \_\_\_\_\_

Duties: \_\_\_\_\_

A. What kind of company or industry is that? What do/did they do or make at the place where you work(ed)?  
\_\_\_\_\_  
\_\_\_\_\_

6. Are/Were you self employed in your own business, practice, or working without pay in a family business (on your main job)?

BRCS6

Yes, self employed .....	1
No, work for someone else .....	2

7. (What is/When you were working, what was) your annual salary before taxes from your job?  
I'll start reading off a list of income ranges; just stop me when I reach the category that includes  
your income.

BRCS7

\$5,000 or less.....	1
\$5,001 - \$10,000.....	2
\$10,001 - \$15,000.....	3
\$15,001 - \$20,000.....	4
\$20,001 - \$25,000.....	5
\$25,001 - \$30,000.....	6
\$30,001 - \$40,000.....	7
\$40,001 - \$50,000.....	8
\$50,001 - \$60,000.....	9
\$60,001 - \$70,000.....	10
\$70,001 - \$80,000.....	11
\$80,001 - \$90,000.....	12
\$90,001 - \$100,000.....	13
\$100,001 or more .....	14
Does not know.....	.97 (ASK A)
Refuses to answer.....	.99 (ASK A)

A. Can you tell me if it was...

BRCS7A

Less than \$25,000 a year or .....	1
More than \$25,000 a year .....	2
DOESN'T KNOW; REFUSED .....	3

8. What is your current marital status?

BRCS8

Married .....	1
IF VOLUNTEERED: Living with a partner .....	2
Divorced .....	3
Separated .....	4
Widowed .....	5
Never Married .....	6

A. How long have you been (married/living together)?

BRCS8A

\_\_\_\_\_ number of years

9. Do you have any children?

BRCS9

Yes.....	1
No.....	2

A. How many children do you have?

BRCS9A

\_\_\_\_\_ number of children

10. Could you please tell me who lives with you in your household? **IF R. LIVES ALONE GO TO Q. 11.**  
**(ASK A-C FOR EACH PERSON IN HOUSEHOLD) (NOTE: IF HOUSEHOLD COMPOSITION HAS CHANGED FROM THE USUAL, CODE FOR COMPOSITION IN THE LAST MONTH),**  
**PROBE: Anyone else?**

A. What is their relationship to you?	B. Sex	C. What was his/her age on his/her last birthday?	
	Male      Female		
Pers. 1. _____	1      2	_____	BRCS10R1 BRCS10S1 BRCS10A1
Pers. 2. _____	1      2	_____	BRCS10R2 BRCS10S2 BRCS10A2
Pers. 3. _____	1      2	_____	BRCS10R3 BRCS10S3 BRCS10A3
Pers. 4. _____	1      2	_____	BRCS10R4 BRCS10S4 BRCS10A4
Pers. 5. _____	1      2	_____	BRCS10R5 BRCS10S5 BRCS10A5
Pers. 6. _____	1      2	_____	BRCS10R6 BRCS10S6 BRCS10A6
Pers. 7. _____	1      2	_____	BRCS10R7 BRCS10S7 BRCS10A7
Pers. 8. _____	1      2	_____	BRCS10R8 BRCS10S8 BRCS10A8
11. So, including yourself, the total number of people living in your household is: _____			BRCS11

12. What was the total income, *during the last year*, of everyone who lived in your household? Total gross income includes things like salary, disability income, social security, interest, and so on. I'll start reading off a list of income ranges; just stop me when I reach the category that includes your income.

BRCS12

\$5,000 or less.....	1
\$5,001 - \$10,000.....	2
\$10,001 - \$15,000.....	3
\$15,001 - \$20,000.....	4
\$20,001 - \$25,000.....	5
\$25,001 - \$30,000.....	6
\$30,001 - \$40,000.....	7
\$40,001 - \$50,000.....	8
\$50,001 - \$60,000.....	9
\$60,001 - \$70,000 .....	10
\$70,001 - \$80,000.....	11
\$80,001 - \$90,000.....	12
\$90,001 - \$100,000.....	13
\$100,001 or more .....	14
Does not know.....	.97
Refuses to answer.....	.99

A. Can you tell me if it was...

BRCS12A

Less than \$25,000 a year or .....	1
More than \$25,000 a year .....	2
DOESN'T KNOW; REFUSED .....	3

### NEED FOR ASSISTANCE/TYPES OF CARE PROVIDED BY CAREGIVER

I'm going to read you a list of activities that your relative may be receiving some assistance with. As I read each activity please tell me if you or someone else is helping her with the activity. (**CIRCLE ALL THAT APPLY**)

	Patient Does it Herself	Caregiver Provides Help	Someone Provides Help	Not Done	<b>Record relationship to the caregiver</b>
1.	Light housekeeping such as dusting. Does your relative do this herself, do you help, does someone else help, or is this not done?	1	2	3 (Who? _____)	8
2.	Heavy housekeeping	1	2	3 (Who? _____)	8
3.	Cooking and meal preparation	1	2	3 (Who? _____)	8
4.	Shopping for clothes & household items	1	2	3 (Who? _____)	8
5.	Grocery shopping	1	2	3 (Who? _____)	8
6.	Bathing and showering	1	2	3 (Who? _____)	8
7.	Home health care tasks	1	2	3 (Who? _____)	8
8.	Getting dressed	1	2	3 (Who? _____)	8
9.	Using the toilet	1	2	3 (Who? _____)	8
10.	Getting in and out of a bed or chair	1	2	3 (Who? _____)	8
11.	Traveling to medical appointments	1	2	3 (Who? _____)	8
12.	Traveling for other purposes (work, visiting, or errands)	1	2	3 (Who? _____)	8
13.	Filling out forms (insurance claims, medical forms, applications for financial benefits)	1	2	3 (Who? _____)	8

		Patient <u>Does it Herself</u>	Caregiver <u>Provides Help</u>	Someone <u>Provides Help</u>	Not <u>Done</u>	Record relationship to the caregiver
14.	Handling banking-related tasks	1	2	3 (Who? _____)	8	BRCA14 BRCA14R1 BRCA14R2
15.	Obtaining information about her illness or treatment	1	2	3 (Who? _____)	8	BRCA15 BRCA15R1 BRCA15R2
16.	Obtaining illness-related financial counseling or advice for her	1	2	3 (Who? _____)	8	BRCA16 BRCA16R1 BRCA16R2
17.	Obtaining illness-related legal counseling or advice for her	1	2	3 (Who? _____)	8	BRCA17 BRCA17R1 BRCA17R2
18.	Arranging for formal home or health care assistance	1	2	3 (Who? _____)	8	BRCA18 BRCA18R1 BRCA18R2

### ILLNESS PREDICTABILITY

1. I usually know when my relative is going to have a good or bad day. Do you...

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRCP1

2. It is clear to me when my relative's illness is getting better or worse. Do you...

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRCP2

3. I can generally predict the course of my relative's illness. Do you...

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRCP3

4. My relative's physical distress is predictable. Do you...

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRCP4

### APPRAISAL OF PERSONAL CONTROL OVER ILLNESS

1. How much personal control do you think you have over the amount of fatigue your relative experiences from day to day? Would you say you have . . .

BRCP1

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

2. How much personal control do you think you have over the amount of discomfort your relative experiences from day to day? Would you say you have . . .

BRCP2

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

3. How much personal control do you think you have over the amount of immobility your relative experiences from day to day? Would you say you have . . .

BRCP3

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

4. How much personal control do you think you have over the amount of pain your relative experiences from day to day? Would you say you have . . .

BRCP4

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

5. How much personal control do you believe you have over the long-term course of your relative's illness, (that is, whether it will improve or at least not worsen in the future)? Would you say you have . . .

BRCP5

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

6. How much personal control do you think you have over the medical care and treatment of your relative's illness? Would you say you have . . .

BRCP6

No control.....	5
Very little control.....	4
A moderate amount of control.....	3
Quite a bit of control.....	2
An extreme amount of control.....	1
DOES NOT APPLY .....	8

## FILIAL OBLIGATION

In this next series of questions, we will be asking you your opinions about help in the home

1. Married children should live close to parents to provide care. Do you . . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC01

2. Children should not be expected to do tasks for their parents. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC02

3. Parents should expect adult children to assist them. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC03

4. It is a child's duty to assist parents. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC04

5. It is preferable to pay a professional for assistance with caregiving. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC05

6. Paying for professional help means a relative is not taking responsibility. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC06

7. It is better to give up a job to provide care than to pay a professional. . .

Strongly agree.....	5
Somewhat agree.....	4
Neither agree nor disagree.....	3
Somewhat disagree.....	2
Strongly disagree.....	1

BRFC07

### CES-D SCALE

I will now read you a list of the ways you might have felt or behaved ***during the past week***. As I read each statement, please tell me the category which best describes how often you have felt this way ***during the past week***.

	Rarely Or None Of The Time (Less Than 1 Day)	Some Or A Little Of The Time (1-2 Days)	Occasionally Or A Moderate Amount of Time (3-4 Days)	Most Or All Of The Time (5-7 Days)
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***During the past week:***

1. I was bothered by things that usually don't bother me. Would you say you felt this way...	1	2	3	4	BRCCES1
2. I did not feel like eating; my appetite was poor	1	2	3	4	BRCCES2
3. I felt that I could not shake off the blues even with help from my friends or family	1	2	3	4	BRCCES3
4. I felt that I was just as good as other people	4	3	2	1	BRCCES4
5. I had trouble keeping my mind on what I was doing	1	2	3	4	BRCCES5
6. I felt depressed	1	2	3	4	BRCCES6
7. I felt that everything I did was an effort	1	2	3	4	BRCCES7
8. I felt hopeful about the future	4	3	2	1	BRCCES8
9. I thought my life had been a failure	1	2	3	4	BRCCES9
10. I felt fearful	1	2	3	4	BRCCES10
11. My sleep was restless	1	2	3	4	BRCCES11
12. I was happy	4	3	2	1	BRCCES12
13. I talked less than usual	1	2	3	4	BRCCES13
14. I felt lonely	1	2	3	4	BRCCES14
15. People were unfriendly	1	2	3	4	BRCCES15
16. I enjoyed life	4	3	2	1	BRCCES16
17. I had crying spells	1	2	3	4	BRCCES17

	<u>Rarely Or None Of The Time (Less Than 1 Day)</u>	<u>Some Or A Little of The Time (1-2 Days)</u>	<u>Occasionally Or A Moderate Amount of Time (3-4 Days)</u>	<u>Most Or All Of The Time (5-7 Days)</u>	
18. I felt sad	1	2	3	4	BRCCES18
19. I felt that people disliked me	1	2	3	4	BRCCES19
20. I could not get "going"	1	2	3	4	BRCCES20
21. I felt alone or cut off from other people	1	2	3	4	BRCCES21

**STATE-TRAIT ANXIETY (MODIFIED - STATE ONLY)**

I am going to read you a number of statements which people have used to describe themselves.  
As I read each statement, please give me the answer which seems to describe how you feel *right now*.

		<u>Not at All</u>	<u>Somewhat</u>	<u>Moderately So</u>	<u>Very Much So</u>	
1.	I feel calm. Would you say this describes how you feel...	1	2	3	4	BRCS1
2.	I feel secure	1	2	3	4	BRCS2
3.	I am tense	1	2	3	4	BRCS3
4.	I feel strained	1	2	3	4	BRCS4
5.	I feel at ease	1	2	3	4	BRCS5
6.	I feel upset	1	2	3	4	BRCS6
7.	I am presently worrying over possible misfortunes	1	2	3	4	BRCS7
8.	I feel satisfied	1	2	3	4	BRCS8
9.	I feel frightened	1	2	3	4	BRCS9
10.	I feel comfortable	1	2	3	4	BRCS10
11.	I feel self-confident	1	2	3	4	BRCS11
12.	I feel nervous	1	2	3	4	BRCS12
13.	I feel jittery	1	2	3	4	BRCS13
14.	I feel indecisive	1	2	3	4	BRCS14
15.	I feel relaxed	1	2	3	4	BRCS15
16.	I feel content	1	2	3	4	BRCS16
17.	I feel worried	1	2	3	4	BRCS17
18.	I feel confused	1	2	3	4	BRCS18
19.	I feel steady	1	2	3	4	BRCS19
20.	I feel pleasant	1	2	3	4	BRCS20

### PHYSICAL BURDEN

1. Some people experience physical strain associated with caring for an ill person. *Since the diagnosis*, how much physical strain would you say you have experienced caring for your relative? Would you say... BRCPB1

A great deal of strain..... 4  
A moderate amount of strain ..... 3  
A little strain or ..... 2  
No strain ..... 1

2. *Since the diagnosis*, have you ever (been called/had to get up) during the night to take care of your relative? BRCPB2

Yes..... 1 (ASK A & B)  
No ..... 2

A. How many times has that happened *since the diagnosis*? BRCPB2A

# of times

B. (ASK IF R. LIVES WITH PATIENT) On those nights when you had to get up to take care of your relative, how many times did you usually get up? BRCPB2B

One time ..... 1  
2 times ..... 2  
3-4 times ..... 3  
5 times or more ..... 4

3. To what extent has caring for your relative affected your energy for your regular daily activities? Would you say that you have... BRCPB3

As much energy as you had before ..... 4  
A little less energy ..... 3  
Somewhat less energy, or ..... 2  
A lot less energy ..... 1

### TIME BURDEN

1. As a result of your caregiving *since your relative's diagnosis*...

	<u>YES</u>	<u>NO</u>	
a. Have you cut down the <i>amount of time</i> you spent doing your regular daily activities? .....	1	2	BRCTB1A
b. <i>Accomplished less</i> than you would like ..... 1	2		BRCTB1B
c. Don't do your regular daily activities as <i>carefully</i> as usual ..... 1	2		BRCTB1C

## SOCIAL BURDEN

1. How frequently do you feel as though you don't have enough time to take care of your own household duties and tasks? Would you say...

Often .....	4
Sometimes .....	3
Rarely .....	2
Never .....	1

BRCSB1

2. *Since your relative's diagnosis*, to what extent has your relative's illness made it difficult for you to establish a daily routine and plan activities? Would you say...

Not at all.....	1
Only a little.....	2
Somewhat.....	3
A great deal .....	4

BRCSB2

3. *Since your relative's diagnosis*, to what extent has your relative's illness made you reduce the amount of time you spend with other family members? Would you say...

Not at all.....	1
Only a little.....	2
Somewhat.....	3
A great deal .....	4

BRCSB3

4. *Since your relative's diagnosis*, to what extent has your relative's illness made you reduce the amount of time you spend with friends, neighbors, and acquaintances?  
Would you say...

Not at all.....	1
Only a little.....	2
Somewhat.....	3
A great deal .....	4
<b>IF VOLUNTEERED:</b> Never did this .....	8

BRCSB4

5. *Since your relative's diagnosis*, to what extent has your relative's illness, made you reduce outside activities, such as going on vacation or having a hobby?

Not at all.....	1
Only a little.....	2
Somewhat.....	3
A great deal .....	4
<b>IF VOLUNTEERED:</b> Never did this .....	8

BRCSB5

## EMPLOYMENT BURDEN

**IF R. IS NOT CURRENTLY EMPLOYED, GO TO NEXT SECTION – “FINANCIAL BURDEN”**

**EVERYONE ELSE, ASK:**

1. *Since your relative's diagnosis*, on how many days would you say you have come in to work late or left early because your relative felt sick and you could not leave her alone, or because you had to escort her to the hospital or medical appointment, or because you had to run errands for her?

BRCEB1

\_\_\_\_\_ # of days

2. *Since your relative's diagnosis*, how many days have you taken off from work as “sick” days, vacation days or personal days due to your relative's illness, such as when she felt sick and could not be left alone, or you had to escort her to the hospital or to a medical appointment, or had to run errands for her?

BRCEB2

\_\_\_\_\_ # of days

3. **IF ANY DAYS, ASK:** How many of these days off from work did you have to take without pay?

BRCEB3

\_\_\_\_\_ # of days

4. *Since your relative's diagnosis*, to what extent has your caregiving affected your ability to concentrate on the job, or in any other ways affected your ability to put in a good day's work? Would you say...

BRCEB4

To a great extent ..... 4  
To some extent ..... 3  
To a small extent ..... 2  
Not at all ..... 1  
IF VOLUNTEERED: Does not apply, self-employed, freelance ..... 8

5. *Since your relative's diagnosis*, to what extent has your caregiving created problems for you with your supervisor or co-workers because of missed time from work or poor work performance? Would you say...

BRCEB5

To a great extent ..... 4  
To some extent ..... 3  
To a small extent ..... 2  
Not at all ..... 1  
IF VOLUNTEERED: Does not apply, self-employed, freelance ..... 8

## FINANCIAL BURDEN

1. *Since your relative's diagnosis*, to what extent has your relative's illness caused you to pass up opportunities to improve your financial situation, such as turning down a promotion, not seeking additional sources of income, or passing up job opportunities? Would you say . . .

BRCFB1

To a great extent .....	.4
To some extent .....	.3
To a small extent .....	.2
Not at all .....	.1

2. Some people find that taking care of someone that is ill can *financially* affect their usual habits and lifestyle. How much has taking care of your relative changed *your financial* habits and lifestyle *since your relative's diagnosis*? Would you say it has made . . .

BRCFB2

Many changes in your usual ways of living .....	.4
Some changes .....	.3
A few changes .....	.2
No changes at all .....	.1

3. Illness can often cause financial problems. How serious are your financial problems due to your relative's illness *since the diagnosis*? Would you say . . .

BRCFB3

Very serious.....	.4
Somewhat serious.....	.3
Not very serious.....	.2
No financial problems at all.....	.1

4. *Since your relative's diagnosis*, have you had any extra expenses because you have been caring for your relative that you would not have had otherwise, such as paying for special food or household items for her or extra transportation or telephone costs?

BRCFB4

Yes.....	.1
No .....	.2

A *Since the diagnosis*, approximately how much money have you spent on these extra expenses? Would you say . . .

BRCFB4A

Less than \$50 .....	.1
\$51 - \$100 .....	.2
\$101 - \$200 .....	.3
\$201 - \$500 .....	.4
\$501 - \$1,000 .....	.5
More than \$1,000 .....	.6

5. (Apart from these out-of-pocket expenses), do you provide any financial support to your relative to help with illness-related expenses?

BRCFB5

Yes.....	.1
No .....	.2

A. *Since the diagnosis*, have you had to, as a result of your relative's illness. . .

	<u>YES</u>	<u>NO</u>	
Use savings .....	1	2	BRCFB5A1
Sell assets like stocks or bonds, your home, a car, major appliances, investment property, or other real estate			
(SPECIFY) .....	1	2	BRCFB5A2
Borrow money? .....	1	2	BRCFB5A3
B. Approximately how much money have you spent on your relative's illness-related expenses to date, including savings, or other assets <i>since the diagnosis</i> ? I am going to read to you some figures; just stop me when I reach the category that includes the amount you have spent.			BRCFB5B
Less than \$1,000 .....	1		
\$ 1,000 - \$3,000 .....	2		
\$ 3,001 - \$5,000 .....	3		
\$ 5,001 - \$10,000 .....	4		
\$10,001 - \$15,000 .....	5		
\$15,001 - \$20,000 .....	6		
\$20,001+ .....	7		

C. Would you say that the money you contribute has been. . .

A great financial hardship .....	3
Somewhat of a hardship .....	2
Not a hardship .....	1

6. *Since the diagnosis*, has your relative had any paid helpers, such as a nurse, housekeeper, or health aide who were hired to help her due to her illness?

Yes .....	1	(ASK A)
No.....	2	

A. Do you help pay for this paid help?

Yes .....	1
No.....	2

7. Has anyone else, such as other family members or friends, helped to pay for any of your relative's illness-related costs *since the diagnosis*?

Yes .....	1	(ASK A)
No.....	2	

A. Who has helped financially? Please tell me their relationship to you? (PROBE: ANYONE ELSE?)

Relationship to Caregiving Relative	<u>Sex</u>		
	<u>Male</u>	<u>Female</u>	
_____	1	2	BRCF7AR1
_____	1	2	BRCF7AS1
_____	1	2	BRCF7AR2
_____	1	2	BRCF7AS2
_____	1	2	BRCF7AR3
_____			BRCF7AS3

### NETWORK OF RELATIONSHIPS (Abbreviated)

We are interested in how illness changes relationships. In this next series of items we ask about how your relationship with your relative has been since her diagnosis and how it was prior to her illness

	<u>Not at all or a little</u>	<u>Somewhat</u>	<u>Very</u>	<u>Extremely</u>	<u>The most</u>	<u>DNA</u>	
1. How much do you and your relative get upset or mad at each other?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR1A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR1B
2. How satisfied are you with your relationship with your relative?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR2A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR2B
3. How much do you tell your relative everything?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR3A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR3B
4. How much do you help your relative with things she can't do by herself?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR4A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR4B
5. How much does your relative treat you like you're admired and respected?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR5A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR5B
6. How much do you and your relative disagree and quarrel?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR6A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR6B

		<u>Not at all or a little</u>	<u>Somewhat</u>	<u>Very</u>	<u>Extremely</u>	<u>The most</u>	<u>DNA</u>	
7.	How happy are you with the way things are between you and your relative?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR7A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR7B
8.	How much do you share your secrets and private feelings with your relative?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR8A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR8B
9.	How much do you protect and look out for your relative?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR9A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR9B
10.	How much does your relative treat you like you're good at many things?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR10A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR10B
11.	How much do you and your relative argue with each other?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR11A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR11B
12.	How good is your relationship with your relative?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR12A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR12B
13.	How much do you talk to your relative about things that you don't want others to know?							
	a. since the diagnosis	1	2	3	4	5	8	BR CNR13A
	b. prior to the diagnosis	1	2	3	4	5	8	BR CNR13B

	<u>Not at all or a little</u>	<u>Somewhat</u>	<u>Very</u>	<u>Extremely</u>	<u>The most</u>	<u>DNA</u>	
14. How much do you take care of your relative?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR14A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR14B
15. How much does your relative like or approve of the things you do?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR15A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR15B
16. How close is your relationship with your relative?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR16A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR16B
	<u>Relative almost always does</u>	<u>Relative often does</u>	<u>About the same</u>	<u>You often do</u>	<u>You almost always do</u>	<u>DNA</u>	
17. Who tells the other person what to do more often, you or your relative?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR17A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR17B
18. Between you and your relative who tends to be the BOSS in this relationship?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR18A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR18B
19. In your relationship with your relative who tends to take charge and decide what should be done?							
a. since the diagnosis	1	2	3	4	5	8	BR CNR19A
b. prior to the diagnosis	1	2	3	4	5	8	BR CNR19B

### **IMPACT OF EVENT SCALE**

Some time ago your relative was diagnosed with breast cancer. I will now read you a list of comments made by people facing similar kinds of stressful life events. As I read each statement, think about your relative's illness and your experiences since her diagnosis and please tell me how often *during the past week* each comment was true for you.

<i>During the past week:</i>	<u>Not at all</u>	<u>Rarely</u>	<u>Sometimes</u>	<u>Often</u>	
1. I thought about it when I didn't mean to. Would you say you this was true for you . . .	1	2	3	4	BRICES1
2. I avoided letting myself get upset when I thought about it or was reminded of it.	1	2	3	4	BRICES2
3. I tried to remove it from my memory.	1	2	3	4	BRICES3
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into mind.	1	2	3	4	BRICES4
5. I had waves of strong feelings about it.	1	2	3	4	BRICES5
6. I had dreams about it.	1	2	3	4	BRICES6
7. I stayed away from reminders of it.	1	2	3	4	BRICES7
8. I felt as if it hadn't happened or it wasn't real	1	2	3	4	BRICES8
9. I tried not to talk about it.	1	2	3	4	BRICES9
10. Pictures about it popped into my mind.	1	2	3	4	BRICES10
11. Other things kept making me think about it.	1	2	3	4	BRICES11
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	1	2	3	4	BRICES12
13. I tried not to think about it.	1	2	3	4	BRICES13
14. Any reminder brought back feelings about it.	1	2	3	4	BRICES14
15. My feelings about it were kind of numb.	1	2	3	4	BRICES15

### PERCEIVED RISK OF BREAST CANCER

1. In your opinion, compared to other women your age, what are your chances of getting breast cancer?  
Would you say . . .

BRCP1

Much lower.....	1
Somewhat lower.....	2
The same .....	3
Somewhat higher.....	4
Much higher .....	5

2. How has your relative's diagnosis of breast cancer affected your perception of your own chances of developing breast cancer? Would you say, it has . . .

BRCP2

Had no effect on me .....	1
Made me feel somewhat more at risk.....	2
Made me feel a lot more at risk .....	3

3. Compared to other women *with* a relative with breast cancer, what are your chances of developing breast cancer? Would you say . . .

BRCP3

Much lower.....	1
Somewhat lower.....	2
The same .....	3
Somewhat higher.....	4
Much higher .....	5

4. Compared to other women *without* a relative with breast cancer, what are your chances of developing breast cancer? Would you say . . .

BRCP4

Much lower.....	1
Somewhat lower.....	2
The same .....	3
Somewhat higher.....	4
Much higher .....	5

**BREAST CANCER QUESTIONNAIRE**

1. What is your height?  
\_\_\_\_ feet \_\_\_\_ inches  
BRCCQ1
2. What is your weight?  
\_\_\_\_ pounds  
BRCCQ2
3. Do you eat 3 or more servings of vegetables a day? (*1 serving is about 1 cup of raw leafy greens or 2 cup of other vegetables, raw or cooked.*)  
Yes .....1  
No.....2  
BRCCQ3
4. Do you usually drink 1 or more servings of alcohol a day? (*1 serving is a can of beer, a glass of wine, or a shot of hard liquor.*)  
Yes .....1  
No.....2  
BRCCQ4
5. How old were you when you started your period?  
Younger than 15.....1  
15 or older .....2  
BRCCQ5
6. Are you currently taking a birth control pill?  
Yes .....1  
No.....2  
BRCCQ6
7. How many children have you given birth to?  
None.....1  
One.....2  
Two or more.....3  
BRCCQ7
8. How old were you when you first gave birth?  
Under 35.....1  
35 or older .....2  
BRCCQ8
9. Have you breast-fed for a total of at least 1 year?  
Yes .....1  
No.....2  
BRCCQ9
10. Are you menopausal? (Including due to hysterectomy)  
Yes .....1  
No.....2  
(ASK A-C)  
BRCCQ10

A. Did you become menopausal before the age of 55?  
Yes .....1  
No.....2  
Yes, due to hysterectomy .....3  
BRCCQ10A

B. Are you currently on hormone replacement therapy? BRCCQ10B

Yes .....1  
No.....2

C. Have you ever been on hormone replacement therapy? BRCCQ10C

Yes .....1  
No.....2

11. Have you ever had benign breast disease? BRCCQ11

Yes .....1  
No.....2

12. Have you ever had a breast biopsy? BRCCQ12

Yes .....1 (ASK A-B)  
No.....2

A. How many breast biopsies have you had? BRCCQ12A  
\_\_\_\_\_ (Number)

B. At what age was your first biopsy? BRCCQ12B  
\_\_\_\_\_ (Age)

13. Do you have any sisters who have ever had breast cancer? BRCCQ13

Yes .....1 (ASK A)  
No.....2

A. How many of your sisters have had breast cancer? BRCCQ13A  
\_\_\_\_\_ (Number)

14. Is your ethnicity mostly Jewish? BRCCQ14

Yes .....1  
No.....2

15. Do you conduct monthly breast self-examinations? BRCCQ15

Yes .....1  
No.....2

16. Do you have regular mammograms? BRCCQ16

Yes .....1  
No.....2

17. Approximately how many months ago did you have your last mammogram? BRCCQ17  
\_\_\_\_\_ (Months)

**Thank you for your cooperation. Is there anything else you'd like to comment on that we have not covered in this interview?**

TIME ENDED:

\_\_\_\_ / \_\_\_\_ a.m./p.m.  
hour minutes

BRCHR  
BRCMN

**INTERVIEWER REMARKS**

1. Did respondent experience or exhibit emotional or psychological problems during the interview?

Yes ..... 1 (ANSWER A)  
No ..... 2

BR CR1

A. What was the problem? \_\_\_\_\_

BR CR1A1  
BR CR1A2  
BR CR1A3

2. Were there any other problems during the interview?

Yes ..... 1 (ANSWER A)  
No ..... 2

BR CR2

A. What was the problem? \_\_\_\_\_  
\_\_\_\_\_

BR CR2A1  
BR CR2A2  
BR CR2A3

3. Was interview conducted in English or Spanish?

English ..... 1 (ANSWER A)  
Spanish ..... 2

BR CR3

A. How much trouble does respondent have understanding English?  
None ..... 1  
Some ..... 2  
A great deal ..... 3

BR CR3A

4. Regardless of whether or not interview was completed in one session, did the respondent *want to* terminate interview before interview was finished?

Yes ..... 1 (ANSWER A)  
No ..... 2

BR CR4

A. At what points and why?  
\_\_\_\_\_

BR CR4A1  
BR CR4A2  
BR CR4A3

5. Did respondent need to complete interview over two or more sessions?

Yes ..... 1 (ANSWER A)  
No ..... 2

BR CR5

A. Reasons given for needing to break up interview  
\_\_\_\_\_

BR CR5A1  
BR CR5A2  
BR CR5A3

6. Date interview started:

\_\_\_\_ / \_\_\_\_ /  
(mo) (da) (yr)

BR6MO  
BR6DA  
BR6YR

7. Date interview completed:

\_\_\_\_ / \_\_\_\_ /  
(mo) (da) (yr)

BR7MO  
BR7DA  
BR7YR

8. Number of interviewing sessions needed to complete interview:

One	.....	1
Two	.....	2
Three	.....	3
Four	.....	4

BR8

9. Name and ID of interviewer:

NAME \_\_\_\_\_ I.D. \_\_\_\_\_

BR9

10. Total time spent interviewing:

\_\_\_\_ /  
hours      minutes

BR10

**Interviewer Comments and observations not otherwise specified:**

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## **APPENDIX E: Topic Guide**

## Topic Guide

### **A. Diagnosis, illness and treatment**

- (A.1) Circumstances leading to patient's diagnosis
- (A.2a) Caregiver's reactions to patient's diagnosis
- (A.2b) Other family member's reaction to patient's diagnosis
- (A.2c) Patient's reaction to her own diagnosis
- (A.3a) Caregiver's reaction to patient's illness and treatment experiences
- (A.3b) Other family member's reaction to patient's illness and treatment experiences
- (A.3c) Patient's reaction to her own illness and treatment experiences
- (A.4a) Caregiver's perception of her general relationship with patient
- (A.4b) Caregiver's perception of changes in relationship with patient since diagnosis
- (A.5) Any reference to caregiver's own experience with cancer or cancer in others (that informed her reaction) / perception/fear of cancer
- (A.6a) Caregiver's reaction to and/or description of formal caregiving (hospital/doctors/treatment)
- (A.6b) Other family member's reaction to and/or description of formal caregiving (hospital/doctors/treatment)
- (A.6c) Patients's reaction to and/or description of formal caregiving (hospitals/doctors/treatment)

### **B. Cancer Risk**

- (B.1) Caregiver's perceived vulnerability to cancer
- (B.2) Caregiver's perception of personal risk factors
- (B.3) Caregiver's informal support experiences
- (B.4) Caregiver's formal support and/or counseling experiences
- (B.5) Medical assessments, guidance, information
- (B.6) Health concerns about the future
- (B.7) Health monitoring plans
- (B.8) Health promoting and disease/prevention practices

### **C. Caregiving**

- (C.1) Circumstances leading to caregiver's assumption of caregiving
- (C.2) Caregiver's levels and extent of caregiving since diagnosis (including examples)
- (C.3) Caregiver's assessment of patient's support needs and support receipt
- (C.4) Caregiver's perception of caregiving ability and performance since diagnosis
- (C.5a) Caregiver's need and receipt of emotional support with caring for patient
- (C.5b) Caregiver's need and receipt of practical assistance with caring for patient
- (C.6) Caregiving burden
- (C.7) Positive aspects of caregiving
  - Note: This may include improvement in relationship with mother, under A4B
- (C.8) Caregiver's attitudes towards caregiving responsibilities
- (C.9) Caregiver's perception of patient's attitude towards caregiver's caregiving

### **D. Lifestyle Changes**

- (D.1) Change in family roles and functioning since illness
- (D.2) Impact of illness and caregiving on relationship with family, friends
- (D.3) Impact of illness and caregiving on work
- (D.4) Future goals, plans
- (D.5) Impact of illness and caregiving on quality of life

### **E. Additional Questions**

- (E.1a) Has dealing with the patient's breast cancer caused changes in fertility issues?
- (E.1b) Has dealing with the patients breast cancer caused changes in child rearing?
- (E.1c) Has dealing with the patients breast cancer caused fears for your descendants' risk of cancer?
- (E.2) In addition to taking care of the patient, are there other members of your family who require your care and assistance (such as children, other elderly or sick relatives)? If yes, ask relationship to respondent and type of help needed from respondent.

### **F. Religion**

### **G. Fear of losing patient**

### **H. Miscellaneous**

## **APPENDIX F: Abstracts from Conferences**

## **PSYCHOSOCIAL CONCERNS EXPERIENCED BY CAREGIVING DAUGHTERS**

**Victoria H. Raveis, Ph.D., Tina Sapienza, C.S.W.,  
Monique Carrero, M.A., and Sheindy Pretter, Ph.D.**

Columbia University, Mailman School of Public Health

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Adult daughters are likely to be a primary source of support and assistance to older women diagnosed with breast cancer, but they have not been a focus of research investigations or supportive services. However, caregiving daughters are likely to be experiencing a high demand for emotional support themselves. The anxiety and concern these women are experiencing over their familial risk status may be compounded by the emotional stress and strain of providing assistance and support to their ill mother, as well as having to deal with the intimate knowledge of their mother's cancer experience afforded by their caregiving experiences. Interviews are being conducted with a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. As part of the data collection, daughters complete an unstructured open-ended interview. The interviews are audio taped, subsequently transcribed into interview text files and then content analyzed. Data collection is ongoing, but analysis of the interviews conducted to date inform our understanding of the psychosocial concerns impacting the caregiving daughters following their mother's diagnosis of breast cancer. The daughters in the sample talk about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability. This heightened sense of vulnerability is translated for some of these caregiving daughters into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in preventive health behavior. Even those women who previously were aware of the importance of regular check-ups and mammography now see their value brought home. For some women this translates into their being more proactive about their health. This awareness of increased risk is also associated with heightened worry and anxiety and can be expressed in hyper vigilant monitoring. Some caregiving daughters, who have an extensive family history of breast cancer, view their mother's diagnosis as an expected, inevitable event. These daughters often present a stoic attitude about their own risk. The breast cancer diagnosis has also impacted their view of their children's risk and their resultant monitoring behavior.

Raveis, V.H., "Psychosocial Concerns experienced by caregiving daughters." Poster presented at the Era of Hope, Department of Defense Breast Cancer Research Meeting, Orlando, FL., September 2002.



## Aging families and breast cancer

**Victoria H. Raveis, PhD**, Joseph L. Mailman School of Public Health, Columbia University, Center for Psychosocial Study of Health and Illness, 100 Haven Avenue, Suite 6A, New York, NY 10032

Limited attention has been given to cancer in the aged, especially among various minority populations. Hispanic elderly primarily rely on family for care in times of illness and female relatives are likely to be the primary source of support and assistance. However, first degree relatives of breast cancer patients are at increased risk for breast cancer themselves. This heightened sense of risk has been associated with increased anxiety levels. A substantial proportion of women at-risk for familial breast cancer hold exaggerated perceptions of their risk and for some the perceived threat is associated with a paralyzing sense of cancer-related worry that severely impacts their ability to function on a daily basis. The anxiety and concern these women may experience may be exacerbated by the strain of providing assistance to their ill mother. Those who are extremely distressed and worried may be incapable of providing the assistance and emotional support their ill parent requires. At-risk women's level of psychosocial adjustment to their familial risk status may also have an adverse effect on their interpersonal relationship with the mother, contributing to unmet patient needs and conflicted support. Such occurrences can impede a cancer patient's recovery. This presentation will discuss how women's perception of their cancer risk effects the quality of their careprovision to their elderly mother. It will also examine the impact of the quality of the patient-caregiver relationship on the older patient's psychological functioning. The data is drawn from interviews conducted with a sample patient-caregiving daughter dyads (n=40).

---

**Abstract ID#:** 47997

**Password:** 791906

**Program Selection:** Gerontological Health

**Topic Selection:** Formal and Informal Caregiving

**Keywords:** Breast Cancer, Aging

**Learning Objectives:** Attendees will: 1) Understand the impact of breast cancer on the aging family 2) Appreciate the psychosocial stresses of informal caregiving 3) Appreciate the the impact of perceived risk of cancer on the quality of the patient-caregiver relationship

**Submitter Email:** vhr1@columbia.edu

**Target Audiences:** Counselors and social workers working with other cancer patients and their families  
Oncologists treating older patients Pastoral care workers working with older families Genetics  
counselors

**Presentation Format:** NoPreference

Raveis, V. H., "Aging Families and Breast Cancer." Podium presentation at the Annual Meeting of the American Public Health Association, Philadelphia, PA, November 2002.

## "Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships"

Victoria H. Raveis, Ph.D.; Sheindy Pretter, Ph.D.; Tina Sapienza, C.S.W.; Monique Carrero, M.A.; and Annemarie Gregory, B.S.

Adult daughters are a primary source of support and assistance to older women diagnosed with breast cancer. However, daughters experience a high demand for emotional support themselves. The anxiety and concern they experience over their familial risk status is compounded by the emotional stress of providing assistance and support to their ill mother and their need to deal with the intimate knowledge of their mother's cancer experience. Interviews with 80 older breast cancer patients and their care giving daughters inform our understanding of the psychosocial concerns and relationship changes (e.g. becoming closer to the ill parent) associated with an aging parent's breast cancer diagnosis. Not only was the diagnosis an event that made daughters realize their own vulnerability but this heightened sense of risk translated into risk management behavioral changes. For some this knowledge impacted their view of their children's vulnerability and highlighted a need for multigenerational health promotion activities.

Learning Objectives: (1) Understand the psychosocial impact of breast cancer on the aging family; (2) Comprehend the impact of perceived risk on the quality of family relationships and careprovision

Raveis, V. H., Pretter, S., Sapienza, T., Carrero, M., & Gregory, A., "Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships." Podium presentation at the Annual Meeting of the Gerontological Society of America, Boston, MA., November 2002.

Raveis, V.H., Pretter, S, Carrero, M, Sapienza, T "Breast Cancer and the Aging Family: Psychosocial Issues and Challenges Facing Adult Daughters." Podium presentation at the First Annual Conference the American Psychosocial Oncology Society (APOS), Orlando, FL, January-February 2004.

PAPER ABSTRACTS OF THE APOS FIRST ANNUAL CONFERENCE

II-6

**Breast Cancer and the Aging Family: Psychosocial Issues and Challenges Facing Adult Daughters**  
Raveis VH, Pretter S, Carrero M, Sapienza T  
*Columbia University, New York, New York, USA*

**Summary:** PURPOSE: As public awareness of a hereditary component to some types of cancer has increased, a growing number of individuals are faced with living with the uncertainty of when or if they may develop cancer. These issues become more complex when at-risk family members are directly involved in their ill relative's care-provision. This presentation will focus on a vulnerable population that has not been a major focus of research investigations or supportive services but are likely to be experiencing a high demand for emotional support – caregiving daughters. The anxiety and concern daughters experience over their familial risk status may be compounded by the stress they encounter providing assistance and support to their ill mother. METHOD: We present findings from an ongoing study of breast cancer survivorship and the family. As part of this investigation, 90-minute in-depth interviews have been conducted with a diverse sample of adult daughters involved in caring for their mothers with breast cancer. Qualitative analysis of the 60 interviews conducted to date inform our understanding of the caregiving daughters' psychosocial issues and concerns following their mother's diagnosis of breast cancer and subsequent treatment course. RESULTS: These interviews document that a mother's cancer diagnosis and involvement in care-provision has a broad psychosocial impact on the adult daughter. Specifically, the daughters' narratives demonstrate that this experience has altered their perception of their mother, intensified their bond with her, presented challenges in mother-daughter interactions, prompted the daughters' comprehension of personal cancer risk, confirmed their membership in an undesirable "club", provided a call to action to reduce their personal risk, redefined their personal values, altered their perceived future, and generated concerns for their children's future. CONCLUSIONS: These findings demonstrate that cancer is a disease impacting the family unit. Caregiving daughters hold a dual status. While they are commonly regarded as part of the care team, they are also affected by the cancer experience and their own perceived risk. Programs and services need to target not only patients but the special needs of affected family members.

Raveis, V.H., Pretter, S., Sapienza, T., Carrero, M., "Psychosocial Issues at-risk women encounter in the provision of care to a relative with breast cancer." Podium presentation to be presented at the Annual Meeting of the American Public Health Association , Washington, D.C., November 2004.



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## **Psychosocial issues at-risk women encounter in the provision of care to a relative with breast cancer**

**Victoria H. Raveis, PhD** <sup>1</sup>, Sheindly Pretter, PhD <sup>1</sup>, Tina Sapienza, MSW <sup>1</sup>, Monique Carrero, MS <sup>1</sup>. (1) Mailman School of Public Health, Columbia University, 100 Haven Avenue, Ste. 6A, New York, NY 10032.

**Background:** As public awareness of a heredity component to some types of cancer has increased, more individuals are living with the uncertainty of when or if they may develop cancer. These issues become more complex when at-risk family members are directly involved in their ill-relative's care. Women caring for a first-degree relative with breast cancer represent a vulnerable population. Through their careprovision, these women obtain intimate knowledge of their relative's breast cancer experience. The emotional stress and burdens associated with having to provide assistance and support to an ill mother, sibling or daughter is compounded by their close identification with their relative's health situation.

**Methods:** Data is drawn from an investigation of breast cancer survivorship and the family. In-depth interviews have been conducted with a diverse sample of women caring for a first-degree relative with breast cancer -- 70% white, non-Hispanic, 26% Hispanic, 4% Black. Qualitative analysis of the women's interviews have delineated their reactions to their mother's, daughters' or sisters' breast cancer diagnosis, the meaning of this event to them, the implications of these issues and the contribution of their careprovision to this experience.

**Results:** The analysis of the women's narratives document that a relative's breast cancer diagnosis and treatment subjects them to a period of crisis fraught with severe emotional distress and life/death concerns that parallels the "existential plight" patients encounter. The women's reports indicate that their first-hand exposure to their relatives' illness increased their sense of personal vulnerability and contributed to a diminished sense of future options. This potent combination of caring for a loved one with breast cancer while worrying about one's own personal risk of developing the disease engendered considerable distress. Specifically, the women's narratives demonstrate that this experience has intensified their bond with the ill relative, while also presenting challenges in their relationship. It has prompted their recognition of personal risk, promoted action plans to reduce their risk, precipitated a re-definition of personal values, altered their perceived future and raised concerns about the risk status of future generations.

**Conclusions:** Support programs and services need to address a broad array of salient

issues and concerns that family members may be encountering. Women caring for a relative with breast cancer hold a dual status. While familial caregivers are commonly regarded as part of the care team, they are also affected by the cancer experience. Clinicians need to appreciate the existential plight familial caregivers may be enduring.

**Abstract ID#:** 89233

**Password:** 185026

**Program Selection:** Medical Care

**Topic Selection:** Women's Health

**Keywords:** Breast Cancer, Caregivers

**Learning Objectives:**

1. Articulate the psychosocial issues confronting at-risk women caring for a relative with breast cancer.
2. Recognize the contribution that care-provision can make in the distress that at-risk women encounter.
3. Describe the impact of breast cancer on the family system.

**Submitter Email:** vhr1@columbia.edu

**Presentation Format:** Oral Only

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## **APPENDIX G: Publications**

PAPER ABSTRACTS OF THE APOS FIRST ANNUAL CONFERENCE

II-6

**Breast Cancer and the Aging Family: Psychosocial Issues and Challenges Facing Adult Daughters**

Raveis VH, Pretter S, Carrero M, Sapienza T  
*Columbia University, New York, New York, USA*

**Summary:** PURPOSE: As public awareness of a hereditary component to some types of cancer has increased, a growing number of individuals are faced with living with the uncertainty of when or if they may develop cancer. These issues become more complex when at-risk family members are directly involved in their ill relative's care-provision. This presentation will focus on a vulnerable population that has not been a major focus of research investigations or supportive services but are likely to be experiencing a high demand for emotional support - caregiving daughters. The anxiety and concern daughters experience over their familial risk status may be compounded by the stress they encounter providing assistance and support to their ill mother. METHOD: We present findings from an ongoing study of breast cancer survivorship and the family. As part of this investigation, 90-minute in-depth interviews have been conducted with a diverse sample of adult daughters involved in caring for their mothers with breast cancer. Qualitative analysis of the 60 interviews conducted to date inform our understanding of the caregiving daughters' psychosocial issues and concerns following their mother's diagnosis of breast cancer and subsequent treatment course. RESULTS: These interviews document that a mother's cancer diagnosis and involvement in care-provision has a broad psychosocial impact on the adult daughter. Specifically, the daughters' narratives demonstrate that this experience has altered their perception of their mother, intensified their bond with her, presented challenges in mother-daughter interactions, prompted the daughters' comprehension of personal cancer risk, confirmed their membership in an undesirable "club", provided a call to action to reduce their personal risk, redefined their personal values, altered their perceived future, and generated concerns for their children's future. CONCLUSIONS: These findings demonstrate that cancer is a disease impacting the family unit. Caregiving daughters hold a dual status. While they are commonly regarded as part of the care team, they are also affected by the cancer experience and their own perceived risk. Programs and services need to target not only patients but the special needs of affected family members.



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*Psycho-Oncology* 13: 1-12 (2004)

1 Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/pon.819

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## 5 EXISTENTIAL PLIGHT OF ADULT DAUGHTERS 7 FOLLOWING THEIR MOTHER'S BREAST 9 CANCER DIAGNOSIS

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11

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### SUMMARY

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Daughters caring for a mother with breast cancer represent a vulnerable population. They are confronted with having to integrate their emotional reactions to their mother's illness while simultaneously processing concerns about their own personal susceptibility. Through their caregiving, daughters obtain intimate knowledge of their mother's breast cancer experience. As part of a study of breast cancer survivorship and the family, in-depth interviews were conducted with a diverse sample of adult daughters caring for their mother with breast cancer. Analysis of the daughters' narratives documents that their mother's cancer diagnosis subjects them to a period of crisis fraught with severe emotional distress and life and death concerns that parallels the 'existential plight' that patients encounter following the cancer diagnosis and inception of treatment. Specifically, the daughters' accounts demonstrate that the diagnosis intensified their bond with their ill mother, while also presenting challenges in their relationship. It precipitated a re-definition of personal values and altered their perceived future. Their mother's illness prompted recognition of increased family risk and rendered daughters with a heightened sense of personal vulnerability. Clinicians need to appreciate the extent to which daughters can be impacted by their mother's cancer experience. Copyright © 2004 John Wiley & Sons, Ltd.

### INTRODUCTION

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There has been growing recognition over the last few decades that cancer is a family illness (Baider *et al.*, 2000; Kristjanson and Ashcroft, 1994; Lewis, 1986; Northouse, 1984; Pederson and Valanis, 1988). That is, in addition to cancer affecting the patients themselves, its diagnosis, treatment, and resolution affect their family members as well, the 'second-order patients' (Rait and Lederberg, 1989). Investigations have documented high levels of emotional and psychological distress among family members of cancer patients (Harrison *et al.*, 1995; Raveis *et al.*, 1998; Toseland *et al.*, 1995), sometimes to an even greater extent than the patients themselves (Keitel *et al.*, 1990; Kornblith *et al.*, 1994; Northouse *et al.*, 2000).

Yet, our understanding of the various ways in which cancer impacts upon the family is still evolving. It has been suggested that as family members learn of their loved one's diagnosis and process its implications they experience a period of crisis fraught with severe emotional distress and life/death concerns (Veach and Nicholas, 1998) that parallels the 'existential plight' patients encounter in the initial months following the diagnosis (Weisman and Worden, 1976-1977). Indeed, studies have documented a range of emotional responses to a relative's cancer diagnosis, including shock and numbness; disbelief and denial; panic, desperation, confusion, and fear; helplessness, frustration, and guilt; and a combination of worry and sadness (Leedham and Meyerowitz, 1999; Northouse, 1984, 1992; Tarkan, 1999).

Efforts to investigate family members' reactions to a cancer diagnosis have mostly centered on spouses of cancer patients (Manne, 1998; Northouse *et al.*, 1991; Raveis, 1999) or on offspring who were either young children or adolescents at the time of their parents' diagnosis (Leedham and

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1 Meyerowitz, 1999; Lewis, 1996; Siegel *et al.*, 1992).  
 2 Little research has been focused on adult children  
 3 struggling with the aftermath of a parent's  
 4 diagnosis with cancer (Oktay, 2004; Raveis *et al.*,  
 5 1999; Wellisch and Lindberg, 2004).

6 Whereas limited attention has focused on how  
 7 the cancer experience affects adult children (Ger-  
 8 mino and Funk, 1993; Wellisch *et al.*, 1996), there  
 9 has been even less investigation of the ramifica-  
 10 tions of a cancer diagnosis on adult children who  
 11 may themselves be at higher risk for developing  
 12 cancer, such as daughters of women with breast  
 13 cancer (Oktay, 2004; Tarkan, 1999; Wellisch and  
 14 Lindberg, 2004). A family history of breast cancer  
 15 is indicative of heightened susceptibility to the  
 16 disease (Lindblom, 1995; Madigan *et al.*, 1995;  
 17 Pharoah *et al.*, 1997). Because of the hereditary  
 18 component of breast cancer, a daughter learning  
 19 of her mother's diagnosis is at the same time  
 20 learning of her own membership in a high risk  
 21 group. That is, she must integrate her reactions to  
 22 her mother's illness while simultaneously pro-  
 23 cessing her reactions to her personal susceptibility.

24 Indeed, as public awareness of a hereditary  
 25 component to breast cancer risk has grown,  
 26 investigations have documented an increased fear  
 27 of cancer and a greater perception of breast cancer  
 28 risk among women with a family history of breast  
 29 cancer (Baider *et al.*, 1999; Gagnon *et al.*, 1996;  
 30 McCaul *et al.*, 1998). This is further complicated  
 31 by daughters' tendencies to overestimate their risk  
 32 of developing cancer (Daly *et al.*, 1996; Gagnon  
 33 *et al.*, 1996; Kash *et al.*, 2000; Lerman *et al.*, 1994,  
 34 1995; Lindberg and Wellisch, 2001; Meiser *et al.*,  
 35 2001; Sagi *et al.*, 1998).

36 These issues may be particularly exacerbated  
 37 when daughters are providing care and support to  
 38 their mothers during her illness. Experiencing first-  
 39 hand the details of their mother's ordeal, caregiv-  
 40 ing daughters may find themselves vicariously  
 41 'living the breast cancer experience' (Chalmers  
 42 and Thomson, 1996). The intimate knowledge of  
 43 their mother's breast cancer experience arising  
 44 from their caregiving involvement may impact the  
 45 daughters' sense of personal risk and increase the  
 46 concerns they associate with the disease. This  
 47 possibility is supported by Erblich *et al.* (2000)  
 48 finding that among women with family histories  
 49 of breast cancer those who had cared for  
 50 their mothers with breast cancer reported higher  
 51 levels of breast cancer-specific distress (i.e. intru-  
 52 sive thoughts and avoidance) than those who  
 53 had not. A similar process has been posited

5 with other diseases in which a family history  
 6 is associated with increased risk. Prohaska  
 7 (personal communication) attributes some of  
 8 the heightened concern and distress experienced  
 9 by adult children caring for an elderly parent  
 10 with Alzheimer's to their 'seeing Alzheimer's  
 11 face' and fearing that this fate awaits them in  
 12 the future.

13 Thus, daughters of breast cancer patients are a  
 14 potentially vulnerable population. Despite grow-  
 15 ing recognition of the necessity to address the  
 16 familial impact of cancer, relatively little research  
 17 attention has focused on adult daughters' reac-  
 18 tions to their mother's breast cancer diagnosis, the  
 19 meaning of this illness to them, and the implica-  
 20 tions of these issues. The purpose of the present  
 21 analysis, then, is to contribute to our under-  
 22 standing of the family's existential plight following  
 23 a cancer diagnosis. Specifically it aims to delineate  
 24 the experiences of daughters of breast cancer  
 25 patients and elucidate their reactions to their  
 26 mother's diagnosis.

## METHODS

### *Eligibility criteria and recruitment*

27 The data were drawn from an investigation of  
 28 informal caregiving to older women with breast  
 29 cancer. Caregiving daughters were identified by  
 30 contacting female breast cancer outpatients from a  
 31 major metropolitan hospital center, whose catch-  
 32 ment area includes diverse socioeconomic and  
 33 racial/ethnic neighborhoods. Potentially eligible  
 34 patients were sent a letter notifying them of the  
 35 study. Included with the letter was a return post  
 36 card with a check-off for those who did not wish to  
 37 be contacted. A clinician researcher then contacted  
 38 patients by telephone to answer their questions  
 39 regarding the investigation, determine the patients'  
 40 willingness to participate, find out whether the  
 41 patients had a caregiving daughter and solicit their  
 42 permission to contact their daughter regarding the  
 43 study. Patients were assured that their participa-  
 44 tion was entirely voluntary and would not affect  
 45 their medical treatment at the hospital center. The  
 46 daughters were accrued in the same manner: a  
 47 letter was sent, followed by a phone conversation  
 48 with the clinician researcher about the study. Only  
 49 those patient-daughter dyads in which both  
 50 members were willing to participate were accrued.  
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1 Caregiver daughters were eligible for the study if  
 3 they were 21 or older, did not have a history of  
 5 cancer, and were involved in providing assistance  
 with breast cancer.

7 *Procedure*

9 As part of the study, each daughter met  
 11 once with a research clinician for a face-to-face  
 focused interview lasting, on average, 53 min.  
 13 The interviewers were female social workers  
 or health educators who had been trained for  
 15 the study in open-ended focused interviewing  
 techniques. Interviews were conducted in English  
 17 or Spanish. A bilingual interviewer conducted  
 19 interviews with participants who preferred to  
 21 be interviewed in Spanish. At the onset of  
 the research meeting, signed informed consent  
 23 was obtained. The protocol for the study was  
 reviewed and approved by an Institutional Review  
 Board.

25 Throughout the interview, the clinician inter-  
 viewers encouraged caregiving daughters to talk  
 27 freely, spontaneously, and in-depth about a variety  
 of issues. Topics addressed during the interview  
 29 included: circumstances leading to the daughters'  
 assumption of caregiving, their reactions to their  
 31 mothers' illness and treatment, changes in their  
 relationships with their mothers since their illness/  
 33 involvement in caregiving, and their caregiving  
 and support provision. The daughters were also  
 35 asked to talk about their perceived vulnerability to  
 cancer and their personal cancer risk factors. The  
 37 interviewers facilitated the flow of information  
 about these issues through neutral prompts,  
 unstructured questions, and by focusing on general  
 39 topics or issues, probing only to encourage  
 elaboration or clarification. Daughters were en-  
 41 couraged to talk spontaneously, determine  
 the flow of the interview, and introduce any  
 43 topic they considered relevant to their experience.  
 This process enabled the daughters' stories  
 45 to emerge on their own, in context, eliciting  
 their personal frame of reference with minimum  
 47 input or influence from the interviewers. The  
 interview was audiotaped, with the daughters'  
 49 permission, for later transcription and narrative  
 analysis. Also at this research meeting, daughters  
 51 completed a brief questionnaire in which they  
 53 reported sociodemographic information and health  
 status.

*Qualitative analysis*

1 The audiotaped focused interviews were trans-  
 3cribed verbatim in computer text files and  
 5 subjected to content/thematic analysis. This al-  
 lowed for the systematic identification of topics of  
 7 discourse (themes) present in the daughters'  
 9 narratives and the specification of relationships  
 among these themes and/or with contextual  
 factors (Polkinghorne, 1989).

11 To facilitate the content analysis of the data  
 we developed an initial set of codes, informed  
 13 by the topic guide, that reflected our provi-  
 sional conception of the factors likely to be of  
 15 theoretical importance in understanding the  
 17 daughters' cancer experiences. These initial codes  
 19 was based on the available literature, our prior  
 research, and clinical experience with familial  
 21 caregivers. As the data gathering proceeded, this  
 23 coding scheme was refined and expanded upon to  
 25 reflect and incorporate emerging insights from  
 the focused interviews that had not been anti-  
 27 cipated and were inadequately captured by  
 29 the initial codes. This revised coding scheme  
 31 was then inserted into the word processing file  
 33 of each transcribed interview, wherever textual  
 35 material relevant to the new code appeared.  
 Pertinent coded material was then retrieved, stored  
 37 in separate text files, and subjected to content  
 39 analysis.

41 Two members of the research team inde-  
 pendently read and analyzed all of the trans-  
 43 cripts; they identified the various themes  
 45 and assigned them specific codes. Inter-rater  
 agreement of the codes assigned was assessed  
 47 on a subsample of interviews and was found  
 to be excellent (i.e. exceeding 90% agree-  
 49 ment). Isolated coding discrepancies were  
 51 resolved through joint discussion and veri-  
 53 fication of the text with other interviews having  
 the same code.

55 The qualitative research design employed in  
 this study is extremely useful for discerning  
 and describing the broad range of reactions,  
 feelings, and concerns experienced by caregiving  
 57 daughters of breast cancer patients. It is not,  
 however, well suited to deriving reliable estimates  
 59 of the true prevalence of the various phenomena  
 61 reported by women in the population under study.  
 For this reason, the findings are not reported  
 63 as percentages of women expressing a particular  
 65 theme. To do so would imply a precision that  
 67 is inappropriate to the methods employed. In  
 69

1 intensive qualitative research, the emphasis is on  
 3 deriving valid insights into a phenomenon, not on  
 5 generalizing the findings to populations or universes (i.e. emphasis is on analytic generalization  
 7 rather than statistical generalization). Thus, our  
 9 data analysis focused on understanding the  
 11 daughters' cancer experiences; i.e. fully articulating  
 13 their reactions to their mothers' diagnosis, the  
 changes they encountered in their relationships  
 with their mothers, and the impact of their  
 mothers' illness and their caregiving involvement  
 on their sense of personal risk and vulnerability to  
 cancer.

15 *Sample characteristics*

19 The findings presented below were derived  
 21 from a sample of 50 caregiver daughters of  
 23 older women with breast cancer. Daughters  
 25 ranged in age from 21 to 62, with a mean age of  
 27 38.3 years (S.D. = 9.6). The majority of daughters  
 29 were between 30 and 50 (72%), 18% were under  
 31 the age of 30, and the remaining 10% were  
 33 50 years or more. Seventy percent of the sample  
 35 self-identified as white, non-Hispanic; almost  
 37 a quarter (24%) as Hispanic; and 4% as black,  
 39 non-Hispanic.

41 Twelve percent of the daughters had a high  
 43 school education or less, about a fifth (18%) had  
 45 some college education, more than a third (38%)  
 47 graduated college, and almost a third (32%)  
 49 obtained a graduate or professional degree.  
 51 Approximately three-quarters (74%) of the women  
 53 were employed at the time of the interview.  
 Only 14% of the daughters lived alone (mean  
 household size = 3.3, S.D. = 1.6). More than  
 half (56%) were married or living with a partner,  
 10% were divorced, and approximately one-third  
 (34%) were never married. Three-fifths (60%)  
 were parents (mean number of children = 2.5,  
 S.D. = 1.4).

53 The average length of time since their mother's  
 diagnosis was 7.5 months (S.D. = 2.8). For almost  
 one-third (30%), the length of time since diagnosis  
 was less than six months; for approximately two-  
 thirds (64%) it was between six and 12 months;  
 with it being greater than one year in 6% of  
 the cases. In over two-thirds (68%) of the cases,  
 their mother's disease was localized. Whereas all  
 of the mothers had undergone surgery, 38% had  
 also received chemotherapy and 46% received  
 radiation.

RESULTS

The daughters' narrative accounts document that  
 the diagnosis of cancer is an event of significant  
 importance to family functioning and demonstrate  
 that patients' family members also undergo a  
 period of crisis and existential plight. The salient  
 issues and impact of the cancer diagnosis that have  
 emerged from an examination of the daughters'  
 interviews can be grouped into three broad  
 categories: (1) emotional responses to the mother's  
 diagnosis, (2) perceived changes in the mother-  
 daughter relationship, and (3) perceptions of  
 personal risk of breast cancer.

(1) *Emotional responses to the mother's diagnosis.* The daughters reported a large range of emotional responses upon learning of their mother's cancer diagnosis and processing its implications. As their narratives below illustrate, the shock, denial, panic, fear, distress and sadness daughters experienced was intense. Some of these reactions dissipated over time. Others, however, were more enduring in their impact.

*Shock.* Chief among the initial responses that daughters reported experiencing was shock. Their reports dramatically documented the intensity with which they recalled being hit with the news of their mother's breast cancer diagnosis. As one daughter recounted in a statement that was typical of this experience: 'I was in shock. ...And you're—you—I was in such a state of shock that you don't—you freeze, and you don't know what to do.' For some, the shock they encountered was precipitated by a lack of forewarning:

It was a shock. I—my heart started racing and—because she started crying as she was telling me. So that kind of—I got very upset. I was crying, I was breathing heavily; I remember I was hyperventilating. It just came out of left field. I had no idea. ... And it just—it was just a complete shock. It was like I got cold-cocked in the face.

Similarly, another daughter recounted how the shock she felt was due to a complete lack of awareness that anyone in their family could be at risk for cancer: 'I was surprised. I was shocked. I was—I just, you know, that word, that 'C' word, I just didn't—we had never had it in our family before, so I was a little, well, 'How could that be?'

*Disbelief.* Closely following the initial shock daughters experienced upon learning the news was a range of other emotions, such as disbelief, panic, and fear. The surprise and lack of forewarning

1 about the event contributed to some daughters  
 3 having a difficult time accepting the diagnosis and  
 5 initially reacting to the news with disbelief. As one  
 7 daughter recalled:

9 Well, at first, I was in, in denial. I just didn't want  
 7 to—a lot of things were going through my mind. . . it  
 9 took me a while for me to really come to terms with  
 reality, that in reality that was cancer.

11 Echoed another—'[E]ven though the doctors are  
 13 saying all this. . . you kind of don't *believe* it.' Some  
 15 daughters found it hard to accept that this  
 17 was actually happening to them. Part of the  
 incredulity associated with the event was their  
 absence of prior exposure to such issues. They  
 found themselves faced with a situation that they  
 knew happened to others, but not to them:

19 And I just was thinking like: this *cannot* be my life.  
 21 But I won't—I don't *believe* this. It was such shock  
 23 and disbelief, like—it is not like my life has—like I  
 25 have friends who like every day there's something  
 else. That her grandmother had a heart attack and  
 her this and that. No, that's not my life. I don't know  
 from these traumas. I don't know from these horrible  
 mishaps. You know? Like I don't know from bad  
 things much.

27 In the wake of their 'shattered assumptions' of  
 29 safety (Janoff-Bulman, 1992) and their realization  
 31 that their family was not immune or protected  
 from health threats, some daughters reported  
 feeling panicked and fearful.

33 *Panic.* The daughters' accounts documented  
 35 that in some instances the panic they experienced  
 37 upon learning the diagnosis was so intense that it  
 39 momentarily immobilized them from taking any  
 purposeful action. As one daughter vividly re-  
 41 counted, '[Y]ou're panicky, you're splatter-  
 ed—your head is splattered all over; your  
 thoughts are jumping—and you don't *know* what  
 direction to go into, you're just *wild*.'

43 The daughters' description of their feelings  
 45 revealed that the panic and desperation they felt  
 47 emanated from a deep-rooted concern for their  
 49 mother's well-being. This consideration is clearly  
 evident in the following description provided by a  
 daughter recalling the panic she felt upon hearing  
 about her mother's breast cancer diagnosis and the  
 frenzy of activity that ensued:

51 I would say just panic, and just—desperation—I just  
 53 started trying to call anybody who I knew who had a  
 wife, a mother, or somebody, to just try to find out as  
 much as I could, to try to help her.

1 *Fear.* Fear was another common response to  
 3 learning of their mother's cancer diagnosis. Cancer  
 5 can be a life-threatening illness. The daughters'  
 7 accounts of their initial response when they heard  
 9 the news illustrate that this information evoked an  
 11 instinctual reaction that raised fears and worries  
 13 about their mother's survival:

15 I was just scared and terrified . . . I didn't know a lot  
 17 about it because I hadn't spoken to my parents yet.  
 19 How advanced was the cancer? I just—all these  
 21 thoughts were running through my head. So I was  
 23 just kind of going off the deep end. I didn't know  
 25 how advanced it was, and I just—I just wanted to  
 27 know that she was okay, that she was going to be  
 29 okay, and no one could answer that for me. You  
 31 know, it was just—it was scary.

33 Similarly, another daughter disclosed: 'I was just  
 35 so scared. So scared. I don't know, it's just a—so  
 37 many feelings at the same time—I got so scared . . .  
 39 lots of things go through your head. And they're  
 41 not the greatest.'

43 Although the initial concerns that daughters felt  
 45 upon learning of their mother's diagnosis usually  
 47 diminished gradually, for some these fears and  
 49 worries have endured. As one daughter noted:

51 I still—to this day—if someone would tell me she will  
 53 be a hundred percent fine, which I don't know if they  
 55 ever will, I'm going to be scared for her life. I'm going  
 57 to be scared for her health and I'll be scared of  
 59 something happening.

61 *Overwhelmed.* Several of the daughters found it  
 63 extraordinarily difficult to deal with their mother's  
 65 diagnosis and recalled being extremely distressed  
 67 and demoralized following the event. In their  
 69 narratives they recounted how it was almost more  
 71 than they could bear. They recalled that they felt  
 73 very drained and were unable to function. Said one  
 75 daughter, 'I completely fell apart. . . . I was in  
 77 complete tears and I had that *pit* in my stomach,  
 79 and it was just a horrible horrible feeling.' Another  
 81 recalled, '[A]t that period of time, I was crying  
 83 so much at home, and I just felt like every time  
 85 my husband saw me, I was a mess.' In some  
 87 instances the daughters' distress was so severe that  
 89 it impacted their ability to relate to other people,  
 91 as this daughter's account illustrates:

93 In the beginning, when it just happened, I couldn't  
 95 deal with it. I didn't want to talk to anyone, I just  
 97 wanted to lay in my bed. Like people would come to  
 99 my house, I would just close them out.

1 For these women the event was traumatizing.  
 3 Not only was their initial distress and demoralization intense, but the upset surrounding this event  
 5 was so strong that subsequent events or circumstances continued to re-awaken these emotional memories. As one daughter articulated:

7 [W]e didn't have phone service, and I'll never forget  
 9 having a cell phone for about a week, and trying to call doctors and get information, and to this day, when I hear that ring, I like jump through the ceiling. We actually changed the ring on the phone, because I  
 11 can't—you know, . . . if I hear that tone, it just hits me—it just brings me back.

15 *Sadness.* Although sadness was another persistent emotional response that daughters reported, it generally emerged over time, once the initial emotional responses abated or receded in intensity. Daughters found it very difficult to see their mothers in this situation and it saddened them. Said one daughter, 'I felt very sad. Very sad for her, very pained by the whole thing.' The sadness daughters experienced was very pervasive and enduring. One daughter commented that: 'I must have cried for days.'

27 Daughters' sadness often accompanied their feeling helpless to remedy the situation. As one daughter shared: 'There was really nothing I could do to help her. You sort of feel helpless. . . . I felt very bad for her. I was sad.' Another daughter's comments illustrate that these feelings were pervasive and shared by the family:

33 Well, when my mother was diagnosed with cancer all of us, her children and whole family thought that the world had ended because it was a very big thing for us . . . . How should I say it? It's a very sad thing when your mother is diagnosed with cancer.

41 *(2) Perceived changes in the mother-daughter relationship.* The breast cancer diagnosis also impacted the mother-daughter relationship. The daughters' stories delineate how this event altered their perception of their mother and created ongoing challenges in their interaction with her.

47 *Seeing their mothers as vulnerable.* One change that daughters commonly reported related to their fundamental perception of their mother as strong and invincible. For many daughters, the cancer diagnosis challenged these long-held images of their mother and represented the first time they perceived her as vulnerable or fragile. As one

1 participant confessed:

3 We call her the Iron Maiden, because she's been through so much, and she just takes it all in stride. And it was the first time that I had actually witnessed her more as, you know, someone who's fragile or delicate.

7 This strongly held preconception of their mother as immune to life's trauma also contributed to the difficulty daughters experienced dealing with the news of their mother's cancer diagnosis. Acceptance of this aberrant event compelled daughters to adjust to a changed reality:

9 For her to get cancer was—I think that's why I went 15 numb, because it just didn't make sense in the way I 17 saw my mother. She—she doesn't get sick. . . . I guess 19 it just brought home that she's susceptible to—to disease, and illness.

21 One daughter's comments succinctly epitomize the life cycle developmental issues that this realization 23 precipitates when she characterized this event as 'a 25 pillar of your life coming down.' For some 27 daughters, their caregiving involuntarily exposed them to their mother's vulnerability and forced 29 them to experience images they viewed with reluctance. The following daughter's statement 31 illustrates how a simple caregiving task—accompanying her mother to obtain a wig—evoked strong emotions and presented profound perceptual challenges:

33 And I took her; my mother sat on the chair, like 35 getting fit for the wig, crying. And like, again, for me, 37 I did not want to be sitting there watching her, because I don't want—I don't want to see her break down. Like I need my vision of her as her being this 39 strong, ultimate—my Mom—like my strength, my support. Like the family backbone.

41 *Seeing their mothers as mortal.* Closely allied 43 to the awareness that their mothers were not immune from illness and suffering, the cancer diagnosis also precipitated life and death concerns. As one daughter commented, 45 'Once your parents get sick, it changes—things change. . . . Your perception of their immortality—or mortality.' Although mortality in old age 49 may be a normative event, the cancer diagnosis raised the possibility that this loss may occur prematurely. For some daughters, this prospect 51 forced them to confront a life cycle transition with which they felt ill-prepared to deal. This 53

1 response is typified in the following thoughts one  
2 daughter shared:

3 Even though I know we all have to die, at  
4 some point—because I've always lived with her and  
5 I have grown so accustomed to living with my  
6 mother, that I—it's just like—it's just *impossible* for  
7 me to really think that my mother's not going to be  
8 there. And, and I think that I have to get maybe a  
9 little bit—stronger.

11 Another daughter expressed holding similar con-  
13 cerns: 'Is she going to live through this?  
15 How many years is she going to be around?  
17 What would I do without her, not having her  
19 around?'

21 The prospect of losing their mother to cancer  
23 was especially difficult for daughters who had  
25 already experienced their father's death. For  
these women, their mother's cancer diagnosis  
raised fears of being orphaned. As one daughter  
recalled: 'One of my initial reactions was, 'Oh my  
God, if something happens to my mother, I—  
I don't have parents anymore.' So that was a little  
scary.'

27 Apprehension over the pain and suffering they  
29 envisioned their mother would endure dying from  
31 cancer contributed to the daughters' worries about  
33 the possibly fatal nature of their mother's illness.  
35 As one daughter described her thoughts: 'For me  
cancer is a bad kind of death sentence that's slow,  
37 and painful.' This concern was echoed by yet  
39 another daughter, who noted, 'So, my biggest fear,  
41 definitely, is that she was going to die, followed by  
43 that she's going to be in a lot of pain. . . I don't  
45 want to lose my Mom to cancer.' As the following  
quote illustrates, even those daughters who had  
readily acknowledged their mother's mortality  
47 were troubled by the circumstances they ascribed  
49 to the process of dying from cancer: 'I know I'm  
51 going to lose her someday. But *normally*, I'm going  
53 to lose her, but I didn't have to lose her *this* way.  
You know, with being sick. You know, being—you know—with cancer.'

45 *Intensified bond with mother.* The cancer diag-  
47 nosis also precipitated marked changes in the  
49 daughters' relationships with their mother. One  
51 commonly acknowledged change was an intensifi-  
53 cation of their relationship with her. As one  
daughter described this impact: 'It just made me  
more aware that I need to love every minute I  
have with her.' Sometimes this intensification in  
the relationship was coupled with a shift in the

daughters' personal priorities, as reflected in the  
following account:

1 I noticed that, all of a sudden, my life, and my  
2 world—everything that I planned, in—nothing  
3 meant—nothing meant anything to me. . . I learned  
4 what she meant to me more than ever. . . I'd say:  
5 'What if I have this house?' And then I said to myself,  
6 'So what—what is it good for?' It means nothing.  
7 Nothing at all.

8 Another daughter's acknowledged that her fear of  
9 possibly losing her mother motivated her to  
11 become her mother's caregiver: 'I felt like—maybe  
13 this is why I became the caregiver. . . I was afraid  
15 not to spend time with her. I was afraid to not be  
17 with her. I was afraid to not be around her a lot.'  
19 For some, though, their mother's cancer diagnosis  
posed a dilemma in their relationship that was  
not easily resolved. As one daughter explained her  
predicament:

21 I think before, I had this idea that my mother wasn't  
23 going anywhere, that she's always going to be there  
25 with me, and I could treat her however I wanted to,  
and she'll always be there. But then when she got ill,  
27 it made me realize that she might not be there  
29 forever, and then I think maybe I should treat her  
better. But then, at the same time, I think maybe I  
don't want to spend that much time with her, because  
if something happens, then I won't miss her at much.

31 *Increased protective and supportive behavior.*  
33 Accompanying the intensification of their bond  
35 with their mothers was an increase in behavior  
37 intended to be protective and supportive. Daugh-  
39 ters described a variety of actions that they  
41 engaged in to shield their mother from distress  
43 and spare her additional emotional pain. One type  
45 of behavior daughters frequently mentioned was  
the effort they took to keep hidden from their  
47 mother their worries and feelings about the cancer  
49 diagnosis and its ramifications. As one daughter  
51 confided, 'I didn't want my mother to know that  
we were worried. Because, letting her know that,  
we probably increase her pain. We probably would  
53 scare her.' Another daughter noted her efforts in  
this regard:

55 I only cried when my mother was not around . . . I  
57 don't know, just in my mind, I felt I needed to be  
59 strong for her. . . it just became that I had to be there  
61 for her and I had to support her, and I had to—I had  
63 to be the strong one.

65 These attempts to be protective and shield their  
67 mother from undue distress and worry were often  
69

1 achieved at some cost to the daughter. As the  
 3 following account illustrates, this effort could  
 5 require intense self-control and exert an emotional  
 toll:

7 It took me a while for me to really come to terms  
 9 with reality, that in reality that was cancer. . . . [T]he  
 11 other problem that I had was, having to *deal* with  
 13 that struggle, and, at the same time, having to present  
 15 myself to my mother, as if it—as if nothing was  
 17 happening. As if, 'Oh, well, so what? We deal with it,  
 it happens.' Well, I was *burning* inside. I was  
 suffering. But I could never let my mother know  
 that I was worried, because, number one, I *knew* she  
 was worried . . . and to me, it was a struggle, because  
 I have to deal with my own anxiety, and, at the same  
 time, I have to be able to show something different to  
 my mother.

19 *Role reversal.* Another lifecycle development  
 21 precipitated by the cancer diagnosis was the  
 23 reversal of roles that accompanied the assumption  
 25 of caregiving activities. For many daughters, this  
 27 represented a marked and unprecedented behav-  
 29 ior shift in their relationship with their mother.  
 31 As one daughter succinctly stated, 'There was a  
 33 definite role reversal, where I would always look to  
 her for support and now she looks to me for  
 support. So, that was a big change.' Daughters  
 35 needed to work through the significance of this  
 37 event and deal with the perceptual changes that  
 39 this life transition represented. The emotions that  
 41 this occurrence can engender are illustrated in the  
 43 following narrative:

45 It was really weird for me, like my mother's always  
 47 taking care of *me*. So like it was—at the very  
 49 beginning stages of me taking care of her was very  
 51 weird. . . . She was scared. And I don't know, I felt  
 like I have to be strong for her. And I felt I had to  
 like—I felt the roles reversed. I had to be comforting  
 her. . . . My instincts were to be the kid, but I  
 couldn't. . . . I feel I have a kid, to a certain extent,  
 sometimes. Like my mother's my child, like I have  
 these obligations to her.

53 (3) *Perceptions of personal risk of breast cancer.*  
 Another aspect of their mother's breast cancer  
 diagnosis was the impact this information made on  
 the daughters' awareness of personal risk. The  
 daughters' narratives document that this can  
 generate an emotional crisis that mirrors their life  
 and death concerns for their mothers and can alter  
 their perceived future.

55 *Realization of personal vulnerability.* For a  
 number of daughters, the unanticipated occur-

1 rence of their mother being diagnosed with breast  
 3 cancer profoundly impacted their perception of  
 5 personal risk. These daughters recalled that prior  
 7 to their mother's diagnosis they had not given  
 9 much thought to the threat of breast cancer. That  
 11 changed as this event destroyed any beliefs they  
 13 may have previously held about immunity from  
 15 cancer. As one daughter observed, '[I]f it happened  
 17 to her, it can happen to me.' Their new status as a  
 19 woman with a family history of breast cancer also  
 21 contributed to some daughters' sense of vulner-  
 23 ability. Commenting on this process, one daughter  
 25 related: '[Y]ou know, beforehand I felt I had no  
 risk whatsoever. And now, with this, I feel I am  
 much—I am at a higher risk, given my history.'  
 Another daughter presented a clear image of this  
 27 perceptual shift following her mother's diagnosis:

29 Before this I never thought about it; not my mother,  
 31 nor my daughter, never. I used to have my annual  
 33 check up, but never thought that in my family this  
 35 will happens. There has never been anybody in my  
 37 family with that illness, nobody. . . . This has been an  
 39 experience that has opened my eyes. It makes you  
 41 think; 'my mother have that illness, I could have it  
 43 too.'

45 One daughter shared how since the diagnosis she  
 47 has become concerned that her awareness of  
 49 personal vulnerability will adversely impact her  
 51 life perspective. As she explained, she wondered:  
 'What would my life *be* like, knowing that I will  
 53 have this risk factor, and how would that affect  
 me, and *would* it affect my ability to enjoy my  
 health in my day-to-day life?'

55 *Confirmation of family history.* Some daughters  
 57 who were already living with a family history of  
 59 breast cancer, regarded their mother's diagnosis as  
 61 further confirmation of their family's vulnerability  
 63 to breast cancer and as adding to their risk of the  
 65 disease. As one daughter explained:

67 I definitely feel as though I'm now at a much higher  
 69 risk for breast cancer than I was. I knew that breast  
 71 cancer was in our family...but with my mother being  
 73 diagnosed, and having had her grandmother die of  
 75 breast cancer, just makes it all that much more—a  
 77 risk for us. Both for my sister and myself, and my  
 79 children.

81 Although for these daughters the diagnosis may  
 83 have been an anticipated event, this awareness did  
 85 not necessarily lessen the emotional intensity of the  
 87 diagnosis. In fact, its occurrence, by affirming a  
 89 long-feared reality, served to enhance long-held  
 91 beliefs.

1 fears of personal vulnerability. As one daughter  
2 described this experience:

3 Coming from the family that I came from . . .  
5 grandparents who had cancer, et cetera, so I feel like  
7 I've always been aware of being vulnerable. At the  
9 beginning, I was—when I realized: 'Oh, I'm higher  
11 risk now.' You know? And my cousins, the daughters  
13 of my aunt, who had the breast cancer, said: 'Oh,  
15 well, welcome to the high-risk club—ha, ha, ha.' And  
17 I didn't—it wasn't a club I was very eager to join. I  
19 felt really scared.

13 For some daughters, knowledge of their mother's  
15 breast cancer not only served to increase their  
17 perception of risk, but it also contributed to their  
19 sense of disease inevitability, reaffirming a previously  
held belief that this was what the future holds for them. This perception is dramatically  
illustrated in the following account:

21 [F]or me, it kicked up a lot of fears of being a  
23 daughter, and that—okay, I'm next in line. . . . I once  
25 heard my mother say that she always felt like she was  
27 waiting for a train, because of our family history.  
Like it was a train she was waiting to get on. You  
know? It was like inevitable. And I guess I feel that  
way now: I'm next.

## DISCUSSION

31 When a family member becomes ill, the illness  
33 experience has ramifications for the entire family  
35 system (Baider *et al.*, 2000; Northouse, 1984). The  
37 focused interviews we conducted with the adult  
39 caregiving daughters of breast cancer patients have  
41 contributed to our understanding of the existential  
43 plight that family members encounter following  
45 the cancer diagnosis of a loved one. These  
47 accounts have documented that caregiving daughters  
49 are a vulnerable population and have provided  
51 insights into the impact and implications of a  
53 mother's diagnosis on her daughter's life. The  
analyses revealed a variety of reactions. These can  
be categorized into one of the following three  
groupings: (1) emotional responses to the mother's  
diagnosis, (2) perceived changes in the mother-  
daughter relationship, and (3) perceptions of  
personal risk of breast cancer.

The daughters reported experiencing a broad  
range of intense emotional responses upon learning  
of their mother's breast cancer diagnosis and  
assimilating its implications. Some of  
these emotions were short-lived, such as the shock

1 and disbelief they encountered. The impact of  
2 other responses, such as panic, fear, distress and  
3 sadness, were more long-lasting. The daughters'  
5 accounts documented the traumatic nature of the  
7 diagnosis and provided compelling examples of  
9 how subsequent occurrences or circumstances  
11 triggered strong emotional memories about the  
13 event.

15 Their stories also established that the breast  
17 cancer diagnosis precipitated marked changes in  
19 their relationship with their mother. The daughters  
21 disclosed how the illness altered their perception of  
23 their mother with many for the first time regarding  
25 her as vulnerable and susceptible to life's adversities.  
27 Their reports delineated how the diagnosis and its  
29 implications intensified the mother-daughter bond.  
31 Daughters shared that their efforts to be protective  
33 and supportive sometimes complicated their interactions,  
35 as they deemed it necessary to shield their mother from extreme personal or  
37 family reactions, out of a belief that such exposure  
39 could be harmful and further increase their  
41 mother's suffering.

43 Although significant progress has been made  
45 in reducing rates of cancer mortality, a diagnosis  
47 of cancer is still often equated with a death  
49 sentence. For some daughters, the cancer diagnosis  
51 forced them to confront a life cycle transition  
53 with which they felt ill-prepared to deal. The  
possibility of such a premature loss engendered a  
cacophony of emotions and a shift in their life  
priorities, as they reevaluated what was important  
to them.

55 In those instances where the mother had  
57 previously been otherwise healthy, the cancer  
59 diagnosis also marked the beginnings of first-time  
61 caregiving, bringing with it a marked role reversal.  
63 The significance of this life cycle turning point is  
65 noteworthy. For many daughters this represented  
67 an unprecedented behavioral shift in their relationship  
69 with their mother. As they were thrown into  
71 the unfamiliar role of giving support and encouragement  
73 to their mother, rather than being the  
75 recipient of such support, they found the experience  
77 challenging and emotionally distressing.  
79 Daughters needed to work through the significance  
81 of this development and deal with the implications  
83 of this life transition.

85 Daughters' caregiving responsibilities played an  
87 integral role by exposing them to images and  
89 realities that challenged long-standing beliefs and  
91 conceptions they held about their mother. In their  
93 reports daughters revealed how involvement in

1 their mother's care placed them in settings that  
 3 exacerbated their distress and contributed to their  
 5 feeling overwhelmed and powerless to alleviate  
 7 their mother's condition.

9 Another ramification of the breast cancer  
 11 diagnosis for daughters was the implication of  
 13 this event for their assessment of their own cancer  
 15 risk. The daughters' accounts documented the  
 17 emotional crisis that this information engendered,  
 19 as it challenged their previously held beliefs about  
 21 immunity from cancer. Simultaneous with their  
 23 efforts to be supportive of their ill mothers,  
 25 daughters were faced with processing the news  
 27 that they themselves were now at increased risk for  
 breast cancer. With their new status as a woman  
 with a family history of breast cancer, they  
 confronted personal life and death concerns that  
 mirrored those they held for their mothers.  
 Daughters who were already living with a family  
 history of breast cancer, regarded their mother's  
 diagnosis as further confirmation of their family's  
 vulnerability to breast cancer. By affirming a long-  
 feared reality, this development enhanced long-  
 held fears of personal vulnerability. For some, it  
 also served to increase their sense of disease  
 inevitability and confirmed their previously held  
 belief that this was what the future held for them.

29 *Clinical implications.* It is important to consider  
 31 the family's response to the cancer diagnosis, as  
 33 the reaction of family members to a patient's  
 35 illness can influence the adjustment of the patient  
 to the illness (Northouse, 1995; Patterson and  
 37 Garwick, 1994) and impact upon the family's  
 39 involvement in care provision (Raveis *et al.*, 1999).  
 The information obtained from these interviews  
 41 may aid clinicians in counseling or supporting  
 43 family members dealing with the cancer diagnosis  
 45 of a loved one. By focusing on the adult caregiver  
 47 daughters' responses to the cancer diagnosis and  
 49 its implications. By focusing on the adult caregiver  
 51 daughters' responses to the cancer diagnosis and  
 53 its implications, the present analysis documents  
 the scope of existential concerns family members  
 may be experiencing. These findings suggest that  
 treatment strategies that exclusively focus on the  
 emotional responses to a family member's illness  
 may inadvertently omit consideration of the broad  
 array of salient issues and concerns that contribute  
 to a family's plight. Consistent with a growing  
 body of evidence in this area (Oktay, 2004; Raveis  
*et al.*, 1999; Wellisch and Lindberg, 2004) the  
 present analysis documents that caregiving daughters  
 may be potentially vulnerable to a range of

1 adverse reactions. As a function of their involve-  
 3 ment in caregiving, they are exposed to various  
 5 aspects of the disease and its treatment, giving  
 7 them a first-hand knowledge of what it might be  
 9 like to personally experience breast cancer. This  
 11 potent combination of caring for a mother with  
 13 breast cancer while worrying about one's own  
 15 personal risk of developing the disease can  
 17 engender considerable distress. Indeed, as the  
 19 daughters' narratives suggest, personal experiences  
 21 with their mothers' illness may increase their sense  
 23 of personal vulnerability and contribute to a  
 25 diminished sense of future options.

27 Clinicians' appreciation of the existential plight  
 29 that families may experience in this type of illness  
 31 situation can be further informed by consideration  
 33 of the family's specific developmental stage and  
 35 the psychosocial concerns that are present at that  
 37 stage (Kristjanson and Ashcroft; 1994). As the  
 39 present analysis has discerned, with the aging  
 41 family, a number of life-cycle developmental issues  
 43 are present that impact the daughter's emotional  
 45 response to their mother's diagnosis, alter the  
 47 mother-daughter relationship and change the  
 49 daughters' perception of personal risk. These  
 51 issues include the role reversal that frequently  
 53 occurs, with the adult daughter becoming the  
 caregivers of their mother, possibly for the first  
 time, as well as daughters' concerns over possible  
 loss, fear of being orphaned, and worry over being  
 next in line for the disease. Awareness that such  
 issues are particularly germane when cancer strikes  
 an older parent may help inform clinical encounters  
 with family members.

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